THE PATIENT SPEAKS: A RETROSPECTIVE ANALYSIS OF THE IN VITRO FERTILIZATION PROCEDURES IN A PROVINCIAL HOSPITAL

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ABSTRACT

This exploratory study tracks the experience of nine infertile couples on the In Vitro Fertilization-Embryo Transfer (IVF-ET) programme at a provincial hospital. Various theoretical perspectives are explored vis a vis the role of women in society in relation to their infertility status. Quantitative data was obtained from questionnaires completed; and qualitative data was obtained through the use of in-depth interviews. The study supports the notion that infertility has both a medical and a psychological component, the latter being unaddressed by the infertility team. Infertility is a couple issue and needs to be addressed as such. The study provides guidelines for future service delivery and therapeutic interventive strategies, and concludes that for effective service delivery, a holistic interventive approach with the inclusion of a clinical social worker is imperative.

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Health is not equivalent to happiness,
surfeit, or success.
It is foremost a matter of being wholly one
with whatever circumstances
we find ourselves in
Even our death is a healthy event if we fully
embrace the fact that we are dying.....
The issue is awareness,
of living in the present.
Whatever our present existence consists of,
if we are at one with it
we are healthy

Latner in Kübler Ross (1986:147)

CHAPTER ONE: INTRODUCTION

1.0 In Vitro Fertilization as a response to infertility

In Vitro Fertilization-Embryo Transfer (IVF-ET) is one of many non-coital reproductive techniques perfected and made available to couples over the last decade. Among available options are non-surgical ovum transfer, frozen embryo transfer, frozen embryo transfer into a surrogate mother and gamete intrafallopian transfer (Sokolov, B, 1987). IVF-ET was initially developed as an option and explored where female patients presented with tubal infertility. More recently, In Vitro Fertilization-Embryo Transfer has become a technique indicated in four groups of couples. These include: those couples with complete failure of ovum pick-up and transport in the female, surgically irreversible; those with defective or inadequate spermatogenesis in the male, or with deficient sperm transport; couples with prolonged unexplained infertility and lastly, those with combined factors of both male and female in origin (Steptoe, 1986:82). Today In Vitro Fertilization has been referred to as the "medicalization of reproduction" (Van Hall, 1985:319). Couples who present with ovulation disorders, endometriosis, male subfertility and unexplained infertility are also included.

IVF-ET: A psychosocially stressful event

It is readily acknowledged that IVF-ET is immensely stressful. Caution against its use as a short-cut for couples with unexplained infertility or infertility factors, which can be treated by alternate means, is indicated. Van Hall (1985) maintains that patients tend to seek this treatment option at their own risk without evaluating the associated feelings that

accompany such a protocol. He suggests that more attention should be paid to the psychosocial and psychosomatic aspects of reproduction, as he asserts that the psychological stress accompanying these procedures is immense and "can affect the delicate mechanisms of implantation and the course of early pregnancy". Van Hall (1985:320) asserts that with more attention to the psychological aspects of embryo transfer and an adequate psychological preparation of these women, pregnancy rates after IVF-ET should increase. It is believed that both organic processes and psychological issues may be interlinked when dealing with the issue of infertility. The intention is not to prove that one's psychological state may have a direct bearing on one's infertility. Rather the emphasis should be on acknowledging that psychological stressors may well be a factor in infertility and may, "exacerbate or diminish infertility and affect the couple's adaptation to both diagnosis and treatment" (Dennerstein & Morse, 1985:842).

Implications for the infertility team and the physician

This fact places the onus on the infertility team and the attending physician to avoid creating the dichotomy between the physical and the psychological. Physicians tend to focus on the medical aspects of infertility often concentrating on the cause and the cure, thereby losing sight of the psychological impact of infertility. The medical component involves numerous medical procedures which exact a great deal of time on the part of both the patient and the medical team. It places an increased responsibility on the attending physician and the medical team to be aware of the psychological factors which may diminish

or exacerbate infertility, and affect the way the individual and couple are adapting and coping with diagnosis and subsequent treatment undertaken. Infertility is a couple issue and therefore it is essential that the couple's expectation of the programme be addressed. Where ambivalence is picked up this should be addressed and where possible, referred to an appropriate resource if such a resource is not available in the unit.

In defence of the medical profession, the couple's needs are not always evident because patients may choose to hide the extent of their emotional pain from physicians. Physicians, who in turn are not trained to pick up the cues which would alert them to a couple's unverbalised distress, may leave the matter unattended. The distress of the infertile is often avoided for various reasons. Firstly, physicians are trained to attend to the complex physiological issues related to infertility and not to its psychological components. Secondly, the brief time period that physicians spend with patients, often mitigate against developing a rapport conducive to discussing the despair and confusion in their lives (Mahlstedt, 1985:342). Patients may interpret the lack of time spent on them as a lack of interest. Furthermore, it is not unusual for the attending physicians to distance themselves from the patients as a function of their own feelings of frustration with the low success rates accompanying a procedure such as this. Lastly, there are physicians who believe that the psychological component of infertility is not important enough to warrant their attention. Often physicians may attempt to attend to the psychological issues themselves. The minimum concern of the physician should be on the couple's ability to deal

with the impact of the physical as well as the medical events involved in the workup. This calls for ongoing education to make the couple aware of the medical aspects of the treatment, thereby providing a basis for communication and involvement between them (Bresnick, 1981:181).

For purposes of clarity the full medical procedures are illustrated in the index so as to aid the reader's understanding of the complexities of this treatment protocol.

Mahlstedt (1985:335) notes that the emotional consequences of infertility represent a struggle for many patients. He maintains that the patients' feelings and attitudes towards infertility and the physician have an influence on the treatment process. The patients' feelings towards the physician can affect their evaluation of the physician's competence. Hence the importance of the physician responding to the personal and psychological needs of their patients.

The psychological impact

Infertile couples face both primary and secondary issues. The primary issues include recognition of a disruption to their life's course caused by infertility, and attempts to reassert control especially in seeking medical advice; finding a reason for their infertility and about infertility in general; and dealing with the negative identity of childlessness in interpersonal and intrapersonal relations. The secondary issues include coping with loss; trying to develop a positive identity; reasons for wanting children; thinking beyond infertility to a life without children and a reassessment of life's

goals and ways of getting needs met (Woollett, 1985:476).

Greenfield & Haseltine (1986) note that the psychological aspects of IVF-ET result from the emotional, financial and psychic demands of the programme, as well as the ethical and moral pressures of the community. Infertility is a crisis which evokes feelings of loss (Bresnick, 1981). Loss is often associated with feelings of mourning and depression (Mahlstedt, 1985). Infertility also impacts on individuals social functioning, creating social conditions of isolation, and career and job problems (Bresnick, 1981:181). Schneider (1984) as quoted in Valentine (1986), observes the individuals' sense of self worth is affected as a function of the fact that these individuals are forced to confront the unquestionable belief carried around from childhood that they would bear children. This disruption in the individuals' perception of their world may serve to alter their perceptions of self worth, goals, feelings of attractiveness, health, prowess, self concept, identity, sexual and bodily functions, body image, and/or can result in significant changes in role performance and role expectations (Valentine, 1986:64).

Infertility diagnosis is different along a time continuum. Up until the point that individuals decide that they are infertile, their body image has been formed. This forces individuals to reorganise their sense of self. "The injury is a narcissistic one, which may raise anxiety. This trauma may be seen to affect the individuals' sense of self with concomitant feelings of anxiety and the lost ideal of becoming a biological parent" (Kraft et al, 1980:623).

1.1 Conceptual framework

The framework of the study is psychosocial. This framework addresses the individual's intrapsychic processes as well as the individual in his/her social context. It recognizes that involuntary childlessness exacts an immense burden on the physical and psychological well-being of the individuals whose lives it touches. Shapiro (1982) as quoted in Goodman & Rothman (1984:81) notes that the crisis of infertility follows the same mourning cycle as described by Kubler-Ross's works on death and dying. These include denial, anger, grief and finally acceptance. The diagnosis of infertility prohibits the transition from one chronological stage in life to another, often bringing with it shifts in roles. It requires a change in the individuals/couples social, physical and psychological status. Infertile couples face the reality of not actualizing the role prescription or expectation that society imposes on them and which is internalized as a belief or value. Infertility requires of the couple a capacity to adapt to the imposition of medical treatment, and secondly to the inner, intrapsychic shifts as a response to this stark reality. In order to cope with this crisis, the individuals needs to retain and manage their internal integration in relation to the environment.

On a personal level it reinforces for individuals the notion that they are out of control in their world. In the broadest sense, there is loss of control of future options and lifestyle. This reality is often accompanied by a perceived loss of emotional control (McCormick, 1980:203). In IVF-ET the crisis may be recurrent over months and years, being triggered by any one failure along the way. With the recurrent

hope and despair following repeated treatment failure, couples are faced with repeated crises of various magnitude. Crisis is not a pathological state and can occur at any stage in the life span. Golan (1978) asserts that couples' basic personality patterns, supportive relationship and resources and supports affect the manner in which they deal with crisis.

1.2 Motivation for the research

Groote Schuur hospital is a State run hospital providing a service delivery covering the Western Cape area. Because it possesses many specialized units, patients from all over the country and neighbouring areas receive treatment here. Being an academic hospital it provides training for students and patient care to those needing medical intervention. Much research is carried out in this setting.

Groote Schuur hospital does not require its patients to be screened psychologically prior to entering an IVF-ET programme. In addition, many couples remain on the programme for years with no supportive or therapeutic intervention provided. Owing to the nature of a large hospital, the patient-doctor contact is often minimal and thus minimises the possibility of a relationship developing between patient and doctor which would allow for the free sharing of concerns and problems.

The inability to be alerted to potential issues confronting a couple also mitigates against the necessary referral to be made by the medical team. The ramification of this is that it is unlikely that the team members are aware of the psychological and social issues confronting the patients whom they treat. The team is often unaware of the way patients

experience the actual treatment at the clinic. This stance of viewing infertility treatment strictly in medical terms, may have detrimental ramifications for the patients.

The researcher became curious as to what the specific issues confronting the patients of this particular clinic are with the view to alerting the medical team of the unaddressed issues facing these couples. It is understandable that because new birth technologies are controlled by the medical profession, the emphasis would steer away from psychosocial factors (Daniels, 1986).

The tendency of the medical profession to split mind from body leads to it being viewed as a medical problem, mitigating against a holistic treatment of a life crisis. Failure to address infertility on a holistic level may impact on the couple in many ways. Confronted by repeated medical failures which manifest themselves in the return of menses, sight must not be lost of the fact that to the couple a failed cycle represents a failure to conceive. Failed conception signifies the death of a potential life. It is the repeated small deaths that couples confront over years in their plight to bear children, that leave them at risk emotionally. The impact which these individuals attribute to this failure on both an intrapsychic as well as on a systemic level therefore, needs to be understood. The researcher therefore proposed to undertake a study to explore the patients' perception of service delivery with its concomitant impact of the treatment on their lives, in a context which is essentially non supportive owing to its medical slant and constraints imposed by a large hospital setting.

Aim of the study

- The study aims to add to the existing body of social work knowledge.
- To recommend to the psychosocial team guidelines for service delivery that best serve the needs, both physical and emotional of the client system.

Objectives of the study

- To provide a patient profile of this small sample.
- To evaluate the patients' perception of service delivery by the infertility team.
- To evaluate the impact of the treatment on the couple, both physically, emotionally and socially.

Underlying assumption

- The existing service delivery needs to be adapted as the needs of the patients are not being adequately served.
- Patients are not being adequately screened for this procedure.
- The IVF-ET programme induces stress for the patients undergoing the treatment.
- The medical team focuses on the biological issues and ignores the psychological issues.
- The emotional struggle of infertility represents a significant struggle for most couples.

1.3 Definition of terms

Fertilization:

The penetration of an ovum by a sperm.

Infertility:

The inability of a couple to achieve a pregnancy after one year of regular unprotected sexual relations or the inability of the woman to carry a pregnancy to live birth.

In Vitro Fertilization - Embryo Transfer (IVF-ET):
The process whereby fertilization of oocytes by sperm takes place in an incubator (outside the body) and the subsequent embryo placed into the uterus via the vagina.

1. 4 Conclusion

In Vitro Fertilization is offered to individuals who are unable to conceive without the aid of medical intervention. The psychological issues involved in infertility are lost sight of by the medical profession because of their training and their focus on cure. The cost to involuntary childless couples of undergoing a treatment such as IVF-ET is immense. Cut off from a major transitional life span event, they face a life crisis involving adaptations both physical, psychological and social. IVF-ET is viewed as a biopsychosocial challenge requiring a holistic approach to treatment. The research attempts to evaluate the service delivery and the biopsychosocial impact of this treatment option.

1.5 Chapter headings

Chapter 1: This chapter will cover the rationale and purpose for the study, and the definition of terms. It looks at infertility as a break in the transitional life span and how IVF-ET is a medical response to this life crisis.

Chapter 2: This chapter will cover an in-depth overview of the most recent and pertinent findings in the field of IVF-ET, highlighting the issues that a treatment programme such as this presents to the couple who choose this treatment modality. Various current dilemmas in the field will be dealt with.

Chapter 3: This chapter explains the choice of research design. It evaluates the pros and cons of the strategy chosen, and mentions the limitations inherent in the study.

Chapter 4: This chapter will discuss the findings and related discussion in the context of available literature.

Chapter 5: This chapter will deal with recommendations of the findings for the infertility clinic, Groote Schuur Hospital, Cape Town in terms of staff and patient management with the view to a more effective service delivery tailored to the clients' needs.

Chapter 6: This chapter will deal with conclusions drawn from of the research.

CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter seeks to explore the findings related to IVF literature over the past fifteen years. It highlights the stressors endemic to this treatment option, and attempts to provide guidelines for intervention which would reflect the reality that both physical and psychological issues are to be addressed in the management of the infertile. It explores the coping methods couples use when undergoing this treatment. The chapter briefly addresses some of the current dilemmas in this treatment option mainly from a feminist perspective.

2.0 Developmental nature of the research

IVF-ET is a relatively new field and as such research in this area has been slow. The research carried out to date can be classified into three areas.

At the outset of this new reproductive technology, research concerned itself primarily with the statistical incidence of infertility in the general population. While findings vary slightly, it is generally estimated that the incidence of infertility is roughly seventeen percent, affecting one in every six couples. A medical diagnosis is established in roughly eighty percent of those couples who are thoroughly tested. Following treatment it is estimated that fifty percent of this group will conceive. It is estimated that the cause of diagnosed infertility can be divided into the following percentages in relation to men and women. In fifty percent of cases the cause is attributable to the female, in thirty percent of the cases it is attributed to the male. In the remaining twenty

percent a combination of factors appears to be present (Kraft, 1989).

The second group of research concerned itself primarily with research into the medical aspects related to new birth technology.

Gradually the focus of research moved to include the psychosocial and psychosomatic aspects of reproduction as well as the importance of screening patients for treatment.

2.1 Implications for physicians

It is readily acknowledged that infertility affects both the mental, marital and social adjustments of the couple (Dennerstein and Morse, 1985:835). Van Hall (1985) asserts that it is important to evaluate the associated feelings confronting these patients. Once the issues confronting the individual and couple are recognized the couple's coping strategies during this form of treatment becomes relevant. It forces the medical profession to view infertility as a biopsychosocial challenge and begs for a response to this reality.

Acknowledging the importance of the physician's role is succinctly portrayed in the following quote:

> They (the patients) do complain, rightfully, about some of the following: the exclusion of their partners from office visits, difficult procedures and important decisions; the feeling of being "worked on" rather than being "worked with"; the refusal of physicians and their staff to listen to the feelings or offer emotional support; the

> inability of a physician to refer to a more expert opinion or to admit that he or she can do more; the inaccessibility of the physician or a member of the professional staff to discuss matters by telephone; and the unwillingness of some physicians to inform clients about community services (Menning, 1980:318)

Issues of responsibility

The question arises as to who is responsible for the treatment of the psychological aspects. This is especially significant in settings where a psychosocial team is not available, or where funding does not allow for the luxury of employing a helping professional. Often contexts such as these need to utilize existing resources such as out-patients psychiatric services. This reality has special relevance to the current study as funding is not available to provide for the psychosocial team approach. Often physicians working in large hospitals are unable to adequately attend to these issues owing to very real time constraints as is the case in the current study. Another factor noted in the literature is the inadequate training of members in a specialized unit such as this in dealing with the psychological aspects of the treatment. Dennerstein & Morse (1985) strongly recommend that at least one member of the IVF-ET team should have training and be assigned to couples undergoing the programme. Ideally this intervention should be ongoing in the form of evaluating patients for IVF-ET, providing support during the workup and during the treatment phase. Weekly follow-up visits with a counsellor are recommended until the counsellor discharges the patients.

2.2 Patients at risk

Patients at risk psychiatrically should also be referred to a psychosocial team. Patients falling into this category include: patients with current psychiatric disorders or who have received past psychiatric treatment; individual patients where doubt exists regarding their motivation for undergoing a treatment option such as this; the stability of their marriage and the couples' respective capacity for parenthood; patients who have an unrealistic expectation of treatment and who are particularly vulnerable to stress. The latter group includes those who lack the necessary confiding and supportive relationships; those who have undergone significant life stress in the preceding year; or those patients who utilize immature, neurotic or psychotic coping strategies; those patients who present with a history of separation from family members during early development; those who have lost a parent before the age of eleven and lastly, those patients who have suffered a depression following a previous loss (Morse & Dennerstein, 1985). Link and Darling (1986) alert the physician to potential danger signals of depression and suicidal ideation experienced by these patients.

2.3 The role of the counsellor

Patients at risk raise the issue, explored in the literature, of the role of the counsellor in IVF-ET clinics and infertility in general. Various psychological tasks are presented on infertility. For those who fail to address these tasks, "the result is not only failure to meet the crisis, but also failure to come to terms with the issues related to parenting as a developmental step in the life cycle" (Kraft, 1989::620-621). The success of a therapeutic

attaining pregnancy. Resolution of the crisis involves a process whereby the couple addressing their emotional state are able to reach a stage of equilibrium as existed prior to the onset of the crisis. Involvement of both partners from inception of treatment is therefore a sine quo non for addressing the crisis holistically. Infertility is dependent on the ability of both partners to reproduce. The team should avoid treating only the partner with the irreversible physical condition requiring an intervention of this nature (Link & Darling, 1986:46). Counsellors can be drawn from many varied disciplines such as nursing, psychology, general practise and social work. Dennerstein & Morse (1985) maintain that it is advisable for the counsellor to work under the supervision of an existing psychiatrist. In a large setting, such as the one in which the research takes place, referral to a psychiatric unit or utilization of its psychiatrist are possible sources to tap, thereby making valuable use of available staff resources.

2.4 Types of counselling for IVF couples

Menning (1979:106) identifies three types of counselling available to American infertile couples. Telephonic counselling which is free and available to all patients exists to provide specific kinds of information on types of treatment, medications, optimising sexual relations for conception and alternative forms of treatment or adoption. This service is not available at Groote Schuur hospital.

The second method is crisis intervention counselling. This usually concerns specific issues the couples are upset or confused about. In these instances, couples often do not know how to ask for help. The value of

trained counsellors reaching out to these couples is vital. This form of counselling is short term and addresses specific problems confronting the individual or couple.

Thirdly, counselling is provided by peer support groups under the supervision of a trained counsellor. These groups can be for both males, females or couples. Weekly groups are held usually extending over fifteen to twenty sessions.

2.5 Initial research on psychological aspects

The need for selection and screening

Much of the initial research carried out in the field of IVF-ET, focused on the need for appropriate selection and screening of patients (Daniels, 1986; Greenfield et al, 1984; Greenfield et al, 1986; Dennerstein & Morse, 1985; Haseltine et al, 1984; and Johnston et al, 1985). Because of the experience of frustration and anxiety confronting couples over the years in their failure to conceive, some authors suggest that, "rather than select for psychiatric help only those couples in whom emotional factors seem to be dominant, it would seem reasonable to conclude a screening interview as part of the initial interview" (Seibel & Taymor, 1982:142). The time and staff constraints of a hospital setting make this suggestion impractical and, it can be argued that a clinically trained person is equally equipped to screen patients and pick up concerns which would necessitate referral to a psychiatrist.

Rationale for screening: The individual and the couple

Greenfield (1986) begs for the screening of candidates on two grounds: firstly, it is asserted that the

assessment of emotional stability of potential patients with the view to meeting the emotional demands of the programme, is important to the integrity of the team. The second issue is argued on the grounds that IVF-ET is particularly stressful. He argues for an assessment of factors such as ambivalence, anxiety, unrealistic expectations of either partners as well as the couple's ability to tolerate stress. The time commitment of couples and potential for dealing with the possible impending loss or disappointment needs to be addressed as well. He acknowledges that the timing of assessments and the instruments to be used in measuring patients status is a difficult one. Medical criteria guidelines for selection include those women with irreparable tubal damage; age limit of late thirties; patients with unexplained infertility and poor semen analysis.

Patient profile

IVF-ET patients' profile show that they tend to have had more contact with counsellors in the past, and were more likely to be on their second or third marriages (Given, 1985). As many as sixteen percent had biological children and another sixteen percent had step children (Haseltine et al, 1985). Couples undergoing IVF-ET score higher on ambition; creativity and independence; and both male and female patients are more upwardly mobile (Link & Darling, 1986). Enormous psychological considerations must be included before this technique is used on patients (Sokolov, 1989:13).

Research supports the notion that infertile women tend to be anxiety prone and emotionally reactive with increased awareness of, and sensitivity to, physical changes and symptoms. It is important to view these

findings tentatively, as they were carried out on a group of patients who had undergone many years of infertility treatment (Morse & Dennerstein, 1985:216). Corea (1985) as quoted in Ardittie (1985:580) sees the differing findings as related to differing contexts. She notes that, "facts are contextual, they depend on who you are, where you are and when we observed them and in which direction we want to go." The method of study, nature of the interviewing tool utilized and the timing of the research vary across studies. It is not easy to compare statistical findings with those gathered through structured or semi-structured interview techniques. This is of particular relevance to this study as the findings are not to be generalised. Rather they must serve as a fertile ground for future ideas about research, and creative ways in which the team can respond to the expressed needs of this minority group. Because IVF-ET is used on women with primarily long standing infertility histories, they tend to articulate their needs and conditions.

Because couples invest so much in this treatment option, it is believed that the psychological tests designed, and the manner in which they are administered, should be done with due consideration. Where the patients are given the assurance that the test results would not jeopardise their chance of entering a programme, information tended to be more candid and less guarded (Haseltine et al, 1984:513). It is important to keep anxiety levels as low as possible.

Age tends to remain static in most studies, with the majority of patients presenting in their mid-thirties. The 20-24 year age group is small, since few patients

tend to graduate to IVF-ET (Johnston et al, 1985). Fewer patients present in the 40-plus age group, as pregnancy risks increase.

Women entering the programme who have either biological or adopted children seem better able to cope with the roller coaster effect and disappointment which accompanies such a stressful programme (Leiblum et al, 1987). Patients experience years of emotional pain and suffering, incorporating such feelings as,

> "sadness, anger, confusion, desperation, hurt, fear and embarrassment, humiliation, disappointment, unfairness and unfulfillment. Behavioural reactions included disorganisation, distractability, exhaustion and fatigue, moodiness, unpredictability and obsessive behaviour and thought" - all attributed to the psychological impact of the infertility experience (Valentine, 1986:63).

In view of the stress induced by being on a waiting list, many women on the programme identify strongly with the role stress plays in their infertility and are thus concerned regarding the impact of waiting for a treatment option such as IVF-ET (Greenfield & Haseltine, 1986).

<u>The psychological well-being of the couple</u>

Few infertility studies have researched the psychological well-being of infertile couples, even though it is widely acknowledged that the treatment protocol significantly elevates the level of stress couples experience. Factors such as the couples personality, their ability to tolerate stress affect

their attitude and behaviour in dealing with a protocol such as this (Greenfield, et al, 1986:79).

During the treatment protocol, the couples' lives become largely centred around reproduction, albeit for a limited period of time. It is important to distinguish between possible stressors induced by infertility per se and those induced or exacerbated by the IVF-ET. The impact of the former feeds into the stress induced by the IVF-ET procedure. Couples present with varying degrees of apprehension towards the programme while undergoing the various stages (Greenfield et al, 1986). The stressors for couples should thus be seen as having multiple sources. It is also important to note that from the findings there is, "no typical patient or couple and that there is a wide range of responses. However, their emotional responses are accentuated during the involvement with IVF-ET, and unless an opportunity is provided for them to work through these problems, they may well face some sort of emotional disintegration" (Johnston et al, 1985:502).

2.6 Stress on the programme

Stress induced through the structure

It is not unusual to find infertility wards on the same floor as the maternity section of the hospital, as is the case in the current study. It can be stressful for a women to gain consciousness following a procedure on the IVF-ET protocol in the same ward as those women who have recently given birth to a live infant. Waiting rooms may often be full of pregnant women alongside those who are infertile. Subsequent treatments may become less stressful as couples are more familiar with their way around the hospital.

Stress induced through isolation

Menning (1975:456) acknowledges the deep sense of isolation and loneliness which infertile couples face. Link and Darling (1986:58) maintains that the, "bonds of understanding and acceptance cannot form in isolation, nor can such couples share their experiences with other infertile couples. It is important that clinicians encourage such couples to monitor their behaviour and balance their need to avoid painful situations with their need to associate with others." The failure to conceive can spread to other activities and roles. Isolation as an adaptive response can result in couples distancing themselves from existing social supports. Utilizing social supports is an essential and effective way of coping and dealing with life's events. Increased isolation increases the dependence of partners on each other. This could serve to strengthen a relationship. However, a fragile relationship or one where many intrapsychic issues are present would be more vulnerable to the stress of a protocol.

Part of the isolation is societally induced. Goffman (1963) views stigma as a form of deviance. The stigma of the infertile couple disrupts the social interaction of these couples because it threatens the legitimacy of these individuals to belong. Coping strategies are needed to allow the stigmatised individuals to navigate their world. This can be done by reducing the salience of the stigma or for these individuals to reevaluate the very meaning which they attribute to the stigma (Elliot et al, 1982). Conception through IVF-ET is an attempt to obviate the stigma of being childless in a society which values childbearing.

Stress induced through crisis points on the programme

The most stressful periods on the programme are the waiting period (which includes the time between embryo transfer and the pregnancy test); the frustration on the first half of the cycle when the patient does not know from day to day what is going to happen to her; and the return of the menstrual cycles which is often accompanied by a deep sense of failure. Premature termination of a cycle can also prove to be highly stressful. Responses to the treatment vary considerably. Some individuals find that subsequent treatments tend to minimize the stress they experience. Other individuals may experience more than one treatment with all its crisis points as too stressful (Greenfield & Haseltine, 1986:124). Treatment serves to heighten bodily awareness which is exacerbated by the treatment procedures and individual expectations (Leiblum et al, 1987).

Stress induced through unrealistic expectations

Couples approaching IVF-ET are made aware of the low success rates. Johnston et al's, (1984) research results show that patients attempting IVF-ET tend to make inaccurate judgements about the likely outcome of such a clinical protocol. Johnston argues that the heuristics used by patients are a function of publicly available information regarding the IVF-ET protocol. Anticipation of a successful outcome is suggestive of a positive attitude towards the clinical procedure and indirectly leads to greater confidence at the time when the procedure is undertaken.

The implication of treating a couple is the awareness that should a partner have an unrealistic expectation or be confused it is highly likely that this perspective will be shared by both partners. Hence

the necessity to keep both partners equally informed. This fact highlights the need for couples to be seen jointly. Leiblum et al, (1987:174) notes that, "although couples are fully informed, both verbally and in written communication, the probability of achieving successful pregnancy is +/- 15 percent, they nevertheless, believe that they will somehow beat the odds." The attending staff on the protocol need to understand the couple's tendency to display both over-optimism and denial regarding the outcome. Johnston et al, (1984:27) notes that:

> since the procedure is undertaken with a psychosocial objective, distress associated with participation in the programme is an important aspect of the evaluation, especially in view of the high failure rate. The procedures would be particularly stressful as each stage carries with it low predictability and a low control in achieving a valued objective factor that contributes to stress in other situations. One might also project that failure on the programme would lead to depressed moods and might even contribute to more lasting depressed mood states.

Despite low success rates, couples have difficulty accepting the possibility of failure (Greenfield et al, 1984). Freeman et al, (1985) in Greenfield (1986:124) emphasizes the, "importance of counselling lies in ways which help the individual recognize the outcome statistic but at the same time retain enough hope to engage in treatment. The counsellor should be alerted to signals from the couple that they may be unrealistic about the outcome of the pregnancy."

Stress induced through lack of locus of control

Infertility highlights for couples a lack of control over their lives. Essentially the couple are called upon to readjust their self concepts and to come to terms with their own and their partner's inability to control bodily functions or their lives in achieving a socially prescribed life's goal.

The impact of failure has special relevance to the deep sense of frustration experienced, especially by the more highly educated sample. This frustration can be seen as the couple's inability to deal with repeated failure in their personal lives in contrast to their potential individual achievements in their professional lives (Link & Darling, 1986). These individuals have often delayed pregnancy in order to establish a career path. They are accustomed to achieving work related goals. Therefore a mental shift is needed to adjust to often repeated failures on the programme, beyond their immediate control.

Characteristic of the procedure is the continuum of emotions ranging from hope to despair. Anxiety surrounding medical procedures serves to exacerbate these effects, often producing mood swings in patients. This serves further to feed into a sense of being out of control. The short lived period of hope in relation to the depressive undertones of the cycle has serious implications for the intervention of the team who view treatment in a holistic fashion. An internal sense of locus of control may serve to explain why couples continue to undergo this treatment protocol and the invasive techniques in order to achieve a parent status. A strong internal locus of control would also indicate the individual's ability to take responsibility for confronting the obstacles

in one's life, rather than being fatalistic regarding the outcome of one's life (Morse & Dennerstein, 1985:216). Feeling that one has the locus of control over one's future gives the individual a sense of power as opposed to powerlessness (Rowland, 1985).

Stress as a function of length of treatment

Length of treatment must be seen as potentially stress inducing for couples. Long term treatment mitigates against the woman dealing effectively with the psychological issues around loss (McGuire, 1975). Long term treatment does not allow for women to address other important issues about career and future life plans. Physicians who aid patients in confronting termination of treatment may be instrumental in aiding these couples in working towards resolution of their loss.

Stress related to sexual functioning

Infertility questions the individual's notion of their own femininity and masculinity. The technological nature of the medical intervention moves the sexual act from the human to the clinical. Performance anxiety may be so severe that it leads to temporary impotence. Sexual dysfunction resulting from the treatment programme warrants team sensitivity to possible dysfunction and the need for appropriate referral. Where necessary, it may be appropriate to withhold treatment until such time as the couple's level of stress and anxiety has been reduced. Fewer men than women endorse the view that their sexual relations had increased (Leiblum et al, 1987). The majority of women have been found to report a worsening of sexual functioning during the protocol (Dennerstein & Morse, 1985:839). The most commonly cited complaint tended to be that the sexual act

became, "mechanical, tied to a calendar, less spontaneous and too purposeful" (Dennerstein & Morse, 1985:839). It is often very difficult for couples to discuss this aspect of their marriage and more so when problems do exist. It calls for a special sensitivity to this area by the staff involved with these patients. Often sexual difficulties may be symbolic of relationship problems within the marriage. Where this is evident it is often useful to intervene with short term therapy in the form of support, education and encouragement (Berger, 1977:142).

Stress confronting the team

The stress induced by an IVF-ET programme, coupled with the psychological adjustment, pervades both the individual receiving the treatment as well as the team (Johnston, 1985). While the latter statement was not explored in the study on a formal level, informal conversations do support this view. Stress experienced by the team manifests itself as a function of the team having to accept and adapt to new technologies and to an ever-changing world. The medical team involved in IVF-ET is also subject to psychological stress as a function of three factors: firstly, often the medical team is left to make decisions based on sparse information regarding the short term and long term effects of this alternate therapy. Secondly, the team can be torn between the hope of new treatment alternatives for their patients on the one hand, and the community's accusations of immorality and unethical experimentation on the other. Lastly, because of the close bond which often exists between patient and medical practitioner, the latter may experience difficulty dealing with the emotions engendered, especially where the probability of unsuccessful treatment remains high (Greenfield &

Haseltine, 1986:119). The team members lack of skill in understanding and dealing with the psychological issues facing these couples could leave the team members stressed.

2.7 Coping mechanisms

Taking control

Coping strategies of the infertile couple vary from individual to individual. Once treatment is sought, medical interventions localise the patients' sense of control as it leaves patients knowing that something is being done and it gives the problem a reality. Woollett (1985) argues that more often women articulate the redefinition of infertility. He further points out that the development of self and the feeling of being the locus of control throughout the lifespan are dependent upon factors which include the gradual progression through a, "number of normative life events such as those around work, personal relations and parents. It is this break from such normative progressions which are perceived as distressing, creating problems for individuals self esteem and self concept of their competency" (Reese & Singer, as quoted in Woollett, 1985:493).

Becoming an expert

Infertility patients and especially those in IVF-ET have a tendency to become infertility specialists. They seek information regarding infertility, though their extensive knowledge is not a, "cognitive appraisal of their position" (Woollett, 1985:478). This preoccupation with infertility by many patients can also be seen as a coping mechanism.

Addressing anxiety engendered by personal factors

Two criteria noted as a need during the protocol are, reduction of anxiety generated by the protocol and attention to stress management of these couples (Morse & Dennerstein, 1985). The medical intervention required, the resultant psychological stress induced for the couple, with the unrealistic expectation of success highlight the need to minimise anxiety through appropriate preparatory work leading up to the protocol. Provision of the psychological needs of the couple should assume the same thoroughness as that provided by the physical assessment. Part of the screening may well involve couples whose psychological profile contraindicate an intervention of this nature at this particular point in time.

Accepting support as a dyad

Pressures of the IVF-ET protocol can serve to highlight the couple's inability to accept their infertility and their apparent inability to resolve these issues. The extent to which these issues have remained unresolved serve as a good indicator as to the amount of stress the couple will be subjected to. The infertility may be the catalyst to open up other unresolved areas and the coping necessary to deal with these issues.

Research supports the notion that the higher the couple score on a marital adjustment scale, the less these couples experience feelings of anger, tension and a greater feeling of vigour (Leiblum et al, 1987). Attention to the personality of the couple specifically in relationship to the couple's ability to tolerate stress is vital (Greenfield et al, 1984:79). This focus can be viewed as a preventive measure utilized by the team in the screening procedure. Because infertile women tend to score

substantially less on levels of marital satisfaction, life contentment and sexual satisfaction (Link & Darling, 1986), supportive interventions may be offered while on the protocol. This should minimize the stress of the protocol, especially in units and in private practice where the ethical stance may be that screening is not necessary - based on the premise that every individual has the right to choose a treatment of choice in the pursuit of a parent status. Women feel more stressed when their husbands do not form part of the treatment process (Link & Darling, 1986). Where husbands are involved in the treatment process, spouses acknowledge that it is most comforting to share the struggle together.

On a more positive note, research supports the notion that many couples reporte that the infertility experience had enhances their marital relationship in the sphere of improved marital communication, sensitivity to feelings of the other partner and a sense of closeness brought about by the realization that they are in the struggle together (Leiblum et al, 1987). This could be a function of a temporary shift in focus from conflictual issues in the marital relationship. Where support is not offered the couple may be left to isolate themselves further through an already stressful period. For this reason the current study involves both husbands and wives.

Dealing with failure anxiety

There should be an awareness on the part of the team for an understanding of how couples deal with the narcissistic hurt which may accompany an individual when the medical treatment fails. An assessment of how patients cope and respond under crisis are good prognostic indicators for the team attending to the

patients. It serves to alert the team to either/or both the medical and mental health issues which are often evoked either directly or indirectly through a protocol such as IVF-ET (Valentine, 1986). This has special relevance for therapeutic intervention. Where treatment fails, patients can present with depression and mourning.

Mourning also brings with it an opportunity for rebirth. It may allow the couple to re-explore their definition of biological parenthood and what it means to them on an individual and couple level. Part of accepting the outcome is learning to cope through planning for the future. Couples are forced to confront available alternatives to biological parenthood or may choose to remain childless. The extent to which a couple are able to create a healthy perspective will serve to aid them in adapting to their future lifestyle. Among the losses are, "bodily failure, doubts about parenting roles and skills, isolation from the world of mothers, recognizing the value of children and needs they would meet for parents" (Woollett, 1985). It results in the withdrawal into a world of inner grief, often not even shared by a spouse. Providing the necessary avenues to deal with this grief forms part of the continuum of holistic service to allow a couple to work through their grief on an internal level, so that in time it may become a peripheral issue.

Symbolically the couple grieve for the children they may never have. The difficulty around grieving is exacerbated by the fact that society provides no socially acceptable avenues through which to mourn a grief such as this. There is no memorabilia, no

funeral. Social lack of perceiving the loss involves lack of social support.

A second avenue of grief is that of the couple's realization that they may not achieve or experience a pregnancy. The inability to work through these losses impact heavily on the marriage. The fertile partner may feel superior, betrayed, and/or guilty, worthless, fearful of abandonment and resentful. It is essential that the couple have at their disposal an available avenue where these feelings can be aired, so that through discussion the issue can be reframed as a "couple" issue (Berk & Shapiro, 1984:44). The avenue should also be opened for the fertile partner who often feels that he/she needs to be the strong one for the infertile mate (Frank, 1984).

Towards resolution of grief

Specific to the IVF-ET programme is the recurrent grieving cycle couples experience who do not conceive on this form of treatment. While women vacillate between anger and despair, men tend to minimize their pain or protect the women from it. Because women are usually the ones to initiate counselling, it is vital that the therapist address this as a couple's issue, extending an arm to the spouse and expressing concern for his/her grief. With the low success rates involved in IVF-ET, couples remain acutely aware that their search for biological motherhood and fatherhood may not be actualized. Each partner is invariably at a different stage of internal grieving which further exacerbates the problem.

> Between the final moment in a doctor's consultation room and the successful resolution of feelings lies a wasteland.

> Emotionally depleted, estranged from sources of support, they search for a way around impediment to their life's plans. Without professional help, many languish indefinitely in suspended animation - able to go neither backward to their hopes of childbearing nor forward to an alternative way of family building (Menning, 1979: 101).

Through counselling, the quality of life for many patients can be enhanced (Bresnick & Taymor, 1979:156). In a hospital context realistic intervention could be short term including support, encouragement and education. Because of the cyclical nature of the treatment process, the sequential nature of therapy becomes highly individual.

Coping through the utilization of counselling services

The need for counselling and psychotherapy in infertility clinics is well documented in the literature (Berger, 1977; Bresnick & Taymor, 1979; Menning, 1980; Hertz, 1982; Greenfield et al, 1987). Programmes that provides avenues for counselling found, that half the patients referred to counsellors turned out to be self-referred. This high figure is indicative of the patients' awareness of their difficulty in coping with the various issues at hand coupled with those that are evoked by a protocol such as IVF-ET. Johnston et al, (1985) notes that once infertility is viewed as a major life crisis it stands to reason that acceptance of infertility does not mean that couples need to block it out. He argues that as a major life crisis, feelings surrounding infertility will remain and produce varying degrees of sadness over time. However, individuals who are infertile can

come to terms with infertility in a constructive, positive way.

2.8 Current dilemmas in new reproductive technology Exploring relevant feminist concerns

Some feminists point to the fact that many women are infertile as a result of iatrogenic (doctor induced) factors such as Intra Uterine Devices and excessive abdominal surgery. It is argued that the medical profession have looked towards IVF-ET as a cure. They have lost sight of the preventive stance which should be taken in combating various contributing variables such as; poor health care, nutrition and environmental factors. A woman-centred approach to both pregnancy and childbirth should emphasise a woman's physical as well as emotional well-being. The well-being of both mother and child is intertwined. This stance calls for a reevaluation of primary health care. Spallone (1989:31) argues that:

> Feminist resistance to the new reproductive technologies can be understood in the context of the women's health movement, where conditions are being created for women-centred health care and medical research. Not embryo centred, not "progress"-centred, but woman centred. A Feminist ethic holds that the aim of reproductive health care and medical research must be focused on what will serve women best, not what serves scientists best. The starting point for reasserting a women centred ethic is the reassertion that women are our bodies and women are ourselves autonomous.

The above quote has special relevance in the South African context. It is commonly acknowledged that poverty is one of the single most major hazards to the health of women and the newborn infant. Without the pursuit of social equity, the changes brought about in both infant and maternal mortality will continue to remain minimal (Womens World, 1986). Women can easily be lost sight of in the ensuing search by largely male medical practitioners in new reproductive technology. The medical profession should guard against reducing women to matter, by ignoring the human component involved in this procedure. This stance makes it easier for the medical profession to deal with the issues of experimenting with human embryos rather than experimenting on womens' bodies (Spallone, 1989:22). Spallone (1989) argues that the split between women and embryos should be avoided as no embryo is disconnected from the woman who is carrying it. The conceptual split between women and embryos mirrors a Western male's view of reproduction thus reflecting masculine thinking.

Scientists argue in turn that womens' interests are taken into account by the "progressive" interests of the medical profession. In Baird et al's study of 1986 on womens' attitudes to new reproductive technology the view of feminists is not supported. By contrast, the majority of women in the study were found to be in favour of IVF-ET treatment. The positive attitudes towards this reproductive technique is not related to social class, parity or age. The only variable which is significant is the religious affiliation of respondents (Baird et al, 1986:165/166). From a couple perspective the objection lies in the fact that, "the commonly used methods for overcoming female infertility not only offends moral

and religious principles, but robs the act of generation its important personal character - the bonds formed between a couple in the natural act of procreation can play a vital part in their relationship throughout marriage and parenthood. They maintain that IVF-ET and its variations are too "mechanistic" and tend to conflict with a woman's intrinsic femininity (Austin, 1989:98).

Value laden selection of IVF-ET patients

Another objection from a feminist perspective is that most IVF-ET clinics require that a couple be married in order to be accepted onto the protocol. The primary motive for this is to gain social acceptability for IVF-ET programmes. This does not take into consideration the rights of those individuals who may wish to bear a child and not marry, or who may follow an alternative lifestyle and therefore not comply with the criteria. This stance is supported by both the British Medical Association which states in their In Vitro Fertilization Guidelines that treatment of this nature should only be made available to those couples who have undergone an assessment and have been found to present with familial stability. Similarly, The Royal College of Obstetricians and Gynaecologists Guidelines give the doctor discretion to refuse treatment on social as well as medical grounds.

IVF-ET necessitates that women view motherhood as a biological relationship to a child. Lorber as quoted in Crowe (1985:552) notes that IVF-ET is not value-neutral:

> it contains values in its designs which reflect the social relations at the time of

> its innovation. In Vitro Fertilization curtails any potential for redefining exclusively on womens' biological reproduction. In so doing it reinforces the notion of the "natural" bond between a mother and her biological children as well as reinforcing the idea that the nuclear family - or indeed one's own biological children - is the only desirable structure of social relations between adults and young children.

Risks involved in this treatment option

There is little undue risk involved in the IVF-ET procedure. However, if the term risk were to include the emotional well-being of the individuals and the impact of the treatment on the couple, there may be an element of risk. The potential risk of a treatment should not outweigh the benefit and there should be little or no harm done to any of the individuals. The issues then in relation to the current study, is the emotional impact that this treatment may have on the couple and how attending to or not attending to the couples' needs places them more or less at emotional risk. The term "risk" means to expose oneself to the chance of harm or loss in terms of the individual's emotional well-being. Recent research categorizes numerous losses of adulthood which are of clinical importance as etiologic factors in depression. These include: loss of health; loss of status or prestige; loss of self esteem; loss of confidence; loss of security; loss of a fantasy or hope of fulfilling an important fantasy; loss of someone or something of great symbolic value. Any one of these losses could precipitate a depressive reaction in an adult. The experience of infertility involves all these losses

(Mahlstedt, 1985:336). These losses place individuals at emotional risk.

It becomes evident that society has been led to accept reproductive engineering once it is introduced and made available. Consequently, "the values underlying the technology and its application are not questioned, nor are the interconnectedness between the next advance and steps further along perceived" (Rowland, 1985:541).

The cost of these techniques to the community in the form of medical benefit payments, the funding of hospital staff and the amount of money utilized in the furthering of research, should in some way hold the medical establishment accountable to the community. The cost to the community should be looked at in human terms as well. This includes the psychological stress which couples undergo during the treatment protocol.

<u>Social factors impinging on the individual</u>

It is argued that cultural bias lies embedded in the notion that women should bear children and not whether women want to bear children. As a function of this stance childless couples remain disenfranchised in our society, the assumption that individuals are not fully functioning adults unless they have had a child is fed. Thus, IVF-ET contributes towards societally entrenched prototypes. Physicians need to acknowledge social forces which "will" women to want to become mothers. While social forces are not the only variables propelling women towards motherhood, it must be acknowledged that there are added forces which impose on women as opposed to men.

While men and women may in fact share common motives for childbearing, there are also different reasons why men and women might wish to bear a child. There is no denying that on a broader level, society and its various institutions serve to imbue in women, through socialization and cultural specific values, that womens' reproductive and sexual function is primary. Mary O Brien , as quoted in Ardittie (1985:582) theorises that men and women have a different reproductive consciousness. Because the consciousness of reproductive experience is different for men and women their conscious experience is therefore also different. "For women, reproduction is a continuous experience in that it starts with intercourse, experience the growth of the embryo, we give birth, may nurse the baby and be primarily responsible for raising it as well. Reproduction is a discontinuous experience for men. Paternity is an idea, while maternity is an experience." This may be an unfair criticism of the actual process, as it implies a significant lack of involvement of the male during the pregnancy experience. Corea notes that the motherhood experience is split into pieces through new reproductive technology (Ardittie, 1985:582). Where one woman can donate an egg, another bring it to term and another raise the child, Corea agues that the power source of women is diminished.

For many women IVF-ET represents their last hope and it is probable that the finer moral and ethical issues may not be uppermost in the patients' minds in their pursuit of biological motherhood. Motherhood, while often a powerful experience also brings with it a host of losses not readily acknowledged - body image, self esteem, financial independence and validation in the workplace. When loss of procreation is seen in

relation to womens' broader loss of political, social and economic power, it is understandable that women may perceive themselves as less valued. How much more so when womens' reproductive function needs to be taken over by medical experts. Such a loss of autonomous reproduction is a further fundamental break with the loss of self (Roberts, 1992). This feeling of inferiority is further fed by a culture where intelligence and creativity are secondary goals which women in society are socialized to strive for.

2.9. Conclusion

The literature has explored the psychosocial implication of a treatment option such as this and the findings emphasize the need to evaluate more closely the psychological factors involved in infertility. This calls for an approach which gives equal importance to both the physical treatment as well as addressing the psychological components. The importance of appropriate screening is seen as reflecting a responsible medical stance to the treatment of infertility. The literature highlights the doctor-patient relationship, suggesting that communication channels be more readily available. This enables patients to experience this treatment as being "worked with" and not "worked on". The aim of this stance is to minimize the many stressors mentioned in the literature findings through providing patients with the necessary coping skills with which to navigate the treatment option representing the end of their infertility career path. The need for counselling is endorsed in the literature. The literature provides various suggestions regarding this need, pointing out that this role could be fulfilled by a variety of helping professionals.

New birth technologies have expanded the choices of women in relative to their reproductive years. Concern is expressed regarding the lack of a preventive womens' health stance by some feminist writers. The chapter touches on some of the objections to new reproductive technology. It is feared that its implementation will blur family boundaries. Inherent risks in this treatment are viewed from an emotional and medical perspective - the implication is to provide the necessary supportive structures in the form of counselling in order to facilitate the unresolved issues and confusion around treatment which these couples experience.

The chapter has acknowledged and explored the social forces that "will" women to bear children. It has also addressed the power relations of women in society and the impact that voluntary childlessness has on the women whose lives it touches.

CHAPTER THREE: METHODOLOGY

Introduction

The research encompassed an evaluation by patients of the service delivery as well as their subjective experience of the IVF-ET programme, Groote Schuur Hospital, Cape Town. Permission to undertake the research was obtained via the Ethics Committee, Groote Schuur Hospital, meeting the following requirements:

- Patients had to be assured of complete anonymity.
- Patients were assured of the utmost confidentiality.
- Patient participation was voluntary.
- Those patients who declined participation in the study were assured that this stance would not affect future treatment acceptance.
- Patients were also assured that they could withdraw from the research at any point.

3.0 Research questions

- Can an interventive strategy be proposed for the individual and the couple where the issues raised by the protocol can be addressed?
- To what extent are the issues surrounding IVF-ET similar or dissimilar for men and women undergoing the experience, and what are the implications of this for an interventive strategy and a responsive service delivery to patients' perceived needs?
- What central issues does the treatment protocol raise for the marital dyad, and how can the clinical social worker address these issues in a treatment paradigm, so that the crisis of infertility can move from a crisis perspective to that of an opportunity for growth?

3.1 Research design

An exploratory research design was chosen since this is useful in laying down the basis for further research (Polansky, 1975). Characteristic of this design method is that small samples, often not rigourously represented, are used for in-depth study in order to arrive at insights to be confirmed later by other levels of research (Polansky, 1975). There is a paucity of literature on service delivery evaluation in IVF-ET clinics.

Sampling strategy

The timing of the study was a difficult one for the unit concerned. There had been a change in personnel heading the unit. New structures and thinking around service delivery had not been clearly assessed and formulated. In that sense the study was timeous. However, because of the state of flux, few treatments were being offered, complicating the sampling procedure. Because of this the researcher was forced to do a retrospective study as opposed to studying the process of the impact of the treatment as they undertook each treatment cycle.

The population from which the sample was drawn was chosen from those patients who had attended the IVF-ET programme at Groote Schuur Hospital during the period between January 1994 to mid-June 1994. All patients interviewed had undergone various treatment cycles in the past and the results of such cycles were known at the time of the interview. All patients had been unsuccessful to date in their attempt to conceive on this treatment protocol.

Sampling design

The sampling design chosen was cluster sampling, comprising a specific population group receiving treatment within a specific time frame. Patients excluded from this sample population were those receiving donor insemination; private patients seen at Groote Schuur; patients not locally resident; and recipients of GIFT and ZIFT procedures. Twenty-two couples had undergone IVF-ET over a six month intake period. All couples had been unsuccessful with the treatment. All the couples had been sent a letter requesting their voluntary participation in this study (Refer to index for copy of the letter). Of the twenty-three letters sent out, nine couples agreed to participate. Of the twenty-two letters sent to patients by the attending physician, reasons given for non participation included: not contactible participants (5); geographical consideration (2); disinterest (1); time constraints (1); patient cancellation (1); fear of research being too traumatic (2); and post operative convalescence (1).

Of the nine husbands in the study, 7 completed both the questionnaire and the conjoint interview. One husband completed the questionnaire only and one did not complete either. The wives of these two were then asked to reflect their partners' views in the interview.

3.2 Method

Motivating for the combined use of qualitative and quantitative research methods

Exploring the impact of infertility on couples' marriages, by definition means exploring a sensitive topic. An analysis of service delivery in a context such as a hospital can also be experienced as

threatening to both staff and the institution concerned. Research in sensitive areas refers also to a cultural sensitivity on the part of the researcher towards the subjects. For example, in this particular research the researcher was sensitive to her gender when it came to exploring areas of sexual concern with male participants across cultural lines.

According to Renzetti & Lee (1993) the qualitative method is especially suited to research of sensitive areas since it allows for a relationship between the researcher and the individual subjects where confidentiality can be clarified. In the current research the researcher needed to intrude into the private lives of couples, and touched on some deeply personal experiences.

In order to tap the richness of the subject matter and provide a more in-depth approach, qualitative research design was chosen. Qualitative research tends to be more field-focused; it allows for the researcher to use herself/himself as an instrument; it looks beneath the observed events to the meaning that these events have for the subjects; it allows for attention to particulars; and lastly qualitative research becomes believable because it is coherent and insightful (Leedy, 1989).

> Qualitative method emphasizes depth of understanding, that attempts to tap the deeper meanings of human experience and that intended to generate theoretically richer observations which are not easily reduced to numbers (Rubin & Babie, 1993:30).

Qualitative and quantitative research can be compatible with one research design, as this allows for a more global picture of the situation and/or event (Leedy, 1989). For this reason the quantitative research method was used in conjunction with the qualitative method in this research with satisfying results. Whereas the qualitative method attempts to tap the richness of the individual experience, the quantitative approach is far more deductive and linear. The quantitative method used lent itself to more systematic gathering of information (e.g. patient profile, infertility history).

A self administered questionnaire was completed by each respondent in a joint interview. This questionnaire was useful in that the desired answers were concrete and quantitative in nature. The advantages of the joint interview method is its appropriateness to complex and sensitive subjects which is an area of concern to social work researchers (Polansky, 1975:133).

Questionnaire and interview schedule

This intended self administered questionnaire was meant to be sent to all respondents in the sample. It was feared that the response rate would be low owing to the complex nature of the questionnaire. It was therefore decided that each couple would complete their respective questionnaires in the presence of the researcher so as to enable them to ask relevant questions. Respondents requested to have the researcher administer both questionnaires in their presence. Slight variations in questions asked distinguished the male questionnaires from the female.

Areas covered:

A. Patient profile
B. Experience of service delivery.
C. Evaluation of follow-up and treatment at the clinic.
D. Evaluation of the clinic service delivery.
E. Impact of the treatment on women and men.

Areas covered in the interview:

- Motivation for wanting children.
- How the decision is reached to participate in the IVF-ET Programme.
- An assessment of how well informed clients are regarding the treatment programme.
- An assessment of who the client is.
- An exploration of the clients' expectations regarding the programme.
- An exploration of the support systems used by patients.
- How clients cope on the programme.

The significance of an interview

Oakley (in Roberts 1981:33) points out that the interviewee needs to perceive the interviewer as sympathetic. Failure to achieve this results in the desired information not being forthcoming. Of relevance to this research is the thinking of Kritzinger as quoted in Roberts (1992) who notes that:

> Womens' own health experiences and accounts are often ignored, trivialized or explained away. The new twist to this situation is that the current vogue for investigating "consumer satisfaction" has led to a tendency in some quarters - not precisely to ignore womens' feelings but to "medicalize" or

> "pathologize" them. For womens' experiences to be expressed in terms which are both meaningful within some form of market, and amenable to management control, they must be reduced and neatly packaged (Roberts, 1992:8).

The reality of this statement in the current study is that both men and women are voiceless. Men are possibly voiceless because the issues are defined as a female issue and not as couple issues.

Pilot study

Two couples formed the pilot study. The findings were incorporated into the final data. Wording of questionnaires was modified following the pilot study, essentially leaving the original format intact.

Data analysis

Quantitative data was mostly graded and subjects were able to choose from a range of multiple choices. The statistics were analysed by hand and tabulated. For the most part only the statistical analysis was presented in the findings in the form of frequency of responses or percentages. The limited length of the thesis prohibited the display of all tabulated data. The qualitative data was interpreted by displaying it in the form of themes, patterns issues, ideas and differences.

3.3 Limitations of the study

The complexity of the questionnaire mitigated against it being posted to participants. This may have positively affected the response rate. The emphasis was on the couples' experience of the treatment and hence the interview was jointly conducted. This form

of interview heightened the accuracy of the data. Individual interviews would have lent themselves to a more in-depth assessment of the impact of infertility on the marital dyad. Because of reduced costs of this treatment at this hospital there was a tendency to attract those patients who could not otherwise afford to go private. The findings were therefore specific to this particular sample and could not be generalized to the larger infertile population.

Rationale and impact of combining the questionnaires in one interview

The questionnaires complemented one another and provided the researcher with the opportunity to explore areas in the in-depth couple questionnaire which were pertinent to a particular couple. This avoided duplication where the information had been provided while completing the questionnaire for husbands and wives. Often discussion surrounding the individual questionnaires had relevance to the in-depth questionnaire - this was then noted.

Advantages of this method

- It allowed for couples to hear and explore differing perceptions held by respective partners which had not been previously voiced.
- Many couples noted that they thus experienced the interviews as cathartic, and having therapeutic value.
- Couples felt empowered by the participation, noting that they had chosen to participate in order to make their concerns known.
- Patients requested feedback suggesting an expectation of accountability.
- Respondents felt free to participate in discussions and to ask questions during the session.

- Couples preferred to be present during the completion of the questionnaire, enabling their spouses' answers to be transparent for them. This method, though not intended initially, increased the reliability of the responses, as spouses corrected and monitored inaccurate responses.

Disadvantages of this method

- Interview time was often lengthy lasting up to two hours.
- Being a retrospective study, the researcher relied heavily on recall.
- Some patients had children, therefore limiting the ability to generalize the findings to a wider population of infertile couples.
  Questionnaires were such that the interviewer would have to complete them for the respondents.

3.4 Significance of the study to social work practice

The need for a helping professional in an infertility unit is motivated from the standpoint that such a person can provide the necessary supportive counselling much needed by patients undergoing IVF-ET. Social work offers an ecological perspective which is suited to aiding a couple experiencing emotional distress engendered by the IVF-ET programme (Greenfield et al, 1987). The role of the clinical social worker in helping couples adapt to the programme, explore their choices, and address intrapsychic, marital issues and social issues aims to significantly reduce their stress levels. Such an intervention restores patients' sense of being in control, it validates patients sense of self worth, and it reflects a caring stance by the infertility team. It mirrors the recognition that infertility is a biopsychosocial condition and that a holistic

treatment paradigm is needed to respond to this reality.

Needleman (1987) found that it is necessary for the social worker to be familiar with the emotional and physical aspects of infertility; the sequential steps in the IVF-ET procedure; the various alternatives open to couples; and referral to existing support groups in the community. Working as a member of a multi-disciplinary team the social worker is seen to contribute in five ways: participates in patient orientation meeting; performs psychosocial evaluations; provides supportive counselling; presents alternatives; and co-leads support groups (Needleman, 1987:139). The social worker needs to adjust his or her intervention to the particular response and needs of the patient.

CHAPTER FOUR: DISCUSSION OF THE FINDINGS

Introduction

This chapter serves to list, interpret and discuss the findings of both the quantitative and qualitative research data. Where possible an attempt is made to integrate the combined findings. The findings cover the patients' profile; infertility history; the various impressions of the patients of service delivery coupled with the impact of IVF-ET programme and infertility on their respective lives.

4.0 SECTION A: PATIENT PROFILE

Worldwide patient profile is known to vary from clinic to clinic. It is a function of many factors such as screening, criteria for treatment and catchment area of the hospitals service delivery.

Cultural breakdown of patients

Cultural breakdown of patients varied. There were two Moslem couples, two Xhosa couples, and five Christian couples. The breakdown of Christian couples were three Anglican, two Methodist, two Roman Catholic and one other. This breakdown may not have been reflected if a larger sample had been used.

Language

The majority (8) of respondents were English speaking, followed by Xhosa (5), Afrikaans (4) and Sotho (1).

Age distribution

Average age for husbands was that of 40 years and for wives 35 years of age. Only two wives were located in the 20-29 year age group, as most women in this age group had not yet "graduated" to the IVF-ET programme. Yet this statistic is of note as with modern treatment

an early diagnosis can be made and patients are now able to enter IVF clinics at a much younger age as a function of the numerous treatment options open to them. The 39 - year plus age group is also poorly represented as a function of their low fecundity (Johnston et al, 1988). Patients may be poorly represented in the older age group for various reasons. Some may have conceived, others may have sought alternative avenues such as adoption.

Educational qualifications

The majority of participants had partially completed their high school training. The comparison in regard to international findings quoted may well have reflected the catchment area that the Groote Schuur hospital draws its patients from. Secondly, the costs were also relatively inexpensive compared to the costs of the same treatment at private clinics.

Marital history

For the majority of women in the sample this was their first marriage. Only one woman had been previously married. The statistic was identical for men. Marriage is a prerequisite for selection at the unit under study. Of the nine couples, all attempted to conceive from the outset of the marriage. As a result of their desire to bear a child, couples used no form of contraception. Despite the fact that no contraception was used, two husbands felt that the timing of the children could have been delayed.

History of bearing children

Children born out of current marriages were fathered/mothered outside a marital union with the exception of one widower. Three men and two women had biological children. It would appear as if there was

a strong commitment to the concept of marriage amongst these couples. Secondary infertility was prevalent in three female respondents.

Referral

The majority of patients (5) were referred to the clinic via private practitioners/gynaecologists. One couple was referred by a family member and another was referred by their house doctor. Two patients were referred from the gynaecological unit of the hospital.

Infertility history in family of origin

The majority of husbands (5) and wives (7) did not present with an infertility history in their family. Some husbands (3) and wives (2) responded positively to the statement. International findings show that the majority of husbands (85%) and wives (60%) reported no history of infertility, with some husbands (5%) and wives (29%) reporting a history (Haseltine et al, 1985:509).

Previous surgery

The majority of women (8) had undergone previous surgery and all female respondents received hormone therapy. This is understandable in terms of their long years of treatments.

Infertility diagnosis

All the women had been informed of their infertility diagnosis. However, not all the men in the sample who were suspected of being sub-fertile were informed of this diagnosis. This information was gleaned from the team after research had been completed. Of the nine couples interviewed only one male was knowingly the infertile partner in the marriage. Of the remaining eight men, four were suspected of being sub-fertile.

In view of the psychological impact of being the infertile partner in the marriage, coupled with the immense shame, guilt and fear of abandonment surrounding this status, it is of concern that the female partners are left to carry the psychological burden of a double infertility diagnosis. Were husbands to be informed of their sub-fertility, it may well impact on the dynamic of the couple as a function of this knowledge being fed into the system. Thirdly, it raises serious ethical issues in terms of pertinent medical information being withheld from the patient system (the couple and the individual). Selective sharing of diagnosis meant that not all patients were clear as to the actual diagnosis of their infertility problem.

The men appeared to be less clear regarding the actual cause of their wives' infertility, probably as a function of the frequency of joint contact between doctor and patient. This was also affected by the realistic work constraints placed on husbands who are often unable to be involved to the same extent as their non-employed wives.

Understanding of diagnosis and the cycle

Actual diagnosis differed from what patients perceived to be as the problem. Women tended to have a better understanding of the possible cause of the infertility problem. The quantitative data reflects that most husbands were sure that they understood the reason for the infertility. Couples had a vague and different understanding of their diagnosis probably as a function of not having been jointly educated while they underwent the treatment programme. Failure to have joint consultations with physicians may also have contributed to this discrepancy.

The more educated the people on the programme, the greater their expressed confusion regarding the fertilization procedures involved, coupled with a need to understand the intricacies of conception. The qualitative data supports the idea that patients required more information around why failure occurred. Patients wanted to know whether more could be done to assist ovum cleavage; whether less stress would ensure better results; whether it was possible to take a drug to ensure that cleavage would take place. Those individuals with lower educational qualifications were less likely to be concerned with the technical understanding of the procedures.

An increased understanding of the programme made it easier to accept the procedures involved in the actual protocol. The flow chart in the passages visually detailing the procedures were of use to patients. Understanding the programme was augmented when patients were able to raise issues with staff or where additional reading aided them in understanding the technicalities of the programme procedures. Successive treatment procedures contributed to a reduction of anxiety in most couples, as the unfamiliar became familiar, and their understanding of the procedures increased.

Initial joint consultation with the doctor served as a fertile ground for patients to be informed and to raise questions. Patients cautioned against doctors using technical jargon which made it difficult for them to understand what was being imparted to them. The doctor-patient relationship was important and was especially relevant in a structure that did not utilise psychological resources for its patients. The majority of women (8) preferred to be seen by one

doctor throughout the treatment protocol. Only one patient felt that it made no difference to her. This closer relationship could meet the patients expressed need to understand, "type of procedures involved in the programme; what was involved in the procedures; what to have expected on a physical level, especially after surgery; what side effects to have looked out for; and what the meaning of the side effects were". Patients felt that their lack of knowledge contributed towards their feelings of anxiety. There was a perception amongst some patients that "passage talk" between patients was experienced as informative. However, the danger of this informal process was that incorrect information also served to distort accuracies and increase anxieties.

Marital history and years infertile

One couple (H) had been married for 16 years, two couples (C and D) for 14 years, one couple (F) for nine years and the remaining five couples (A,B,E,G,and I) had each been married for four years respectively. The average number of years married equalled nine. All the couples concerned had been trying to conceive from the outset of their respective marriages. Couple C had entered into the marriage knowing that there was an infertility problem and had been on various forms of treatment for the entire duration of their marriage.

Couples C, D, F, G and H had been on infertility treatment for years equal to their years married. Couples B and E had attempted infertility for half of their respective married life. Only one couple had been on infertility treatment for a one year period.

Motivation for remaining on treatment

Potts (1980:638) notes that it is not clear whether the decision related to parenthood has become another stressful transition in adult development. Crowe (1985) notes that a contributing factor to women remaining on IVF-ET treatment was a function of them needing to explore all alternatives to biological motherhood before they could accept a child-free life. Motherhood and marriage was part of these womens' life plans. It is possible that the men were as motivated as a group to continue with the treatment as is illustrated in the following quote:

> When we speak to the men, when the wife is not in earshot, they (the men) say that they do it (IVF-ET) out of pressure. But as he speaks he realizes that he wants it as much as his wife. He does not admit it (Husband in couple A).

Number of cycles to be undertaken

All couples expressed a willingness to be on the programme. None of the couples had planned how many cycles they would undertake in advance. The following extract reflects the uncertainty experienced by couples regarding planning future options.

> In this business you can't say X number (of cycles). Sometimes your body can't take that number of cycles. You need to stop the cycles for a while and then start again. (Wife in couple E)

Over time various criteria were mentioned as significant in determining the number of cycles the couples were prepared to undertake in the future.

Optimism on the programme

Being on the programme filled couples with a sense of hope and optimism which probably explains why most of the couples did not initially feel vulnerable in the marriage. Crowe (1985) notes that once women are on a programme they experience their participation to have a momentum all of its own. Failure after the first cycle was expressed as difficult to accept by couples A, E, I and J. Repeated failures were experienced as discouraging by all couples interviewed. The quantitative data supports the expressed optimism to continue with future cycles. Eight couples were committed to a future treatment programme. One couple (J) was prepared to discontinue treatment should another cycle fail, as the wife asserted that she did not believe she would be successful on the treatment. Treatment was continued because her husband wanted a child, and he believed that the treatment would ultimately prove to be successful.

The couples' expectation of conceiving while on the treatment varied. The quantitative data reflects that on average half the male and female respondents were optimistic regarding the successful outcome of the treatment, with the remaining half being either neutral or sceptical. Despite the latter statistic, couples remained on treatment for years. Lack of optimism of the programme was often a function of repeated treatment failures coupled with a verbalised sense of disillusionment.

The emotional investment in treatment is high, even though there is a low probability of success. This lack of success negatively affected the couples' expectation of success on treatment cycles. All the couples believed that despite low success rates, they

would "still beat the odds," as is found in the literature (Leiblum et al, 1987). All couples expressed confusion around the probability statistics of achieving a pregnancy on a programme such as this. The literature supports the notion that patients inaccurately judge their success at possible conception on the programme (Johnston et al, 1984). Obviously, this optimism serves as a coping mechanism for couples. It was evident that failure to conceive over time had significantly added to depressed mood states, notable in the infertile partner. Costs of the treatment seemingly correlated with this sense of negativity. There was no visible evidence of the programme's success. Couples did not see other pregnant couples, they did not visually experience children born from IVF-ET in the corridors, as is the practise in some clinics. This left couples doubting the competency of the medical team and doubting whether they should have sought alternate treatment at a private clinic.

Crowe (1985:551) refers to the media's coverage of successful mothers receiving this treatment to represent IVF as a 'panacea' for infertility, by focusing on positive results obtained through this treatment option. The quantitative data shows that on average the female respondents were more optimistic of success than their male counterparts. Most respondents (10) were optimistic, followed by those who were neutral (5). One respondent was sceptical and one respondent was non committal. Generally one partner seemed to be more optimistic than the other, and this could possibly have fluctuated over years of treatment.

Future treatment cycles

Despite past treatment failures couples optimism concerning the success of future cycles varied. Four women (A, F, H, and I) and six men (A, C, D, G and I) maintained that they were optimistic regarding an ultimate successful outcome. It was evident that spouses did not share the same levels of optimism and the researcher was left to wonder what impact this had on the supportive role of spouses towards each other in the marriage. Four women (B, C, G and E) and one male (B) were neutral. One woman (D) an d one male (H) stated that they were sceptical.

The reason for wanting children

Reasons for wanting children varied from couple to couple. Three wives and two husbands had fathered children outside the current union. Those respondents who had biological children from a previous liaison or marriage/union maintained that it would not have been experienced as traumatic should no children be born from the current union. There was no need to prove their fertility, compared with those spouses who had never fathered or mothered a child. All individuals who, despite having fathered or given birth to biological children in the past, saw their commitment to the infertility treatment as a reflection of their commitment to the current marriage.

Reasons for wanting children were subjective. All couples expressed the notion that a marriage was synonymous with children. The word most often mentioned to describe what childlessness would mean to them as a couple and individually was "emptiness".

Having children also imbued couples with a meaning to their particular life together as is illustrated in the following quote:

> We worry about what we are working for. Who is going to eat this money when we die? (Wife in couple F).

Children were perceived as carrying on the family name, a desire to parent, to fulfill oneself as a woman or a man, to meet social expectations. Erikson (1968) as quoted in Goodman & Rothman (1984) viewed the primary developmental task undertaken in adulthood to be generativity. Erickson believed that where this was not accomplished, individuals faced a developmental crisis. The crisis concerned the ego having to face a developmental task which it could not master. This lack of mastery lead to injuries to one's self esteem and threat to sexual identity.

With the exception of one husband, who specifically wanted a son, there were no distinguishable differences between the motivation of the men and the women to bear a child. The importance of bearing a child was reflected in the expectation of the culture of origin. Both Xhosa couples explained that from the time of marriage the social pressure to bear a child and to prove fertility was strong for both men and women. Where the wife was unable to conceive in this culture, the men explained that it was culturally important for them to prove their virility. The men remained married as a function of their commitment to their wives. However, they felt obligated to bear children, even if this meant bearing a child with another woman. Women in unions such as these feared abandonment and divorce, despite their husbands'

protestations that they would not leave them, as illustrated by the following quote from a Xhosa woman:

> If you can't have children, the men use the women and the women use the men. It is a sad thing. They (other women) try and take the husband away. You can't protest. They try and take the relationship away. You can't protest because you don't have kids. The other woman can say, "I'm having a baby and you don't have kids." You don't understand what happens in our culture (Wife in couple F).

This quote highlights the fact that parenthood may well differ for men and women. The social environment and culture of these women made it impossible for them to escape the feelings of difference. Crowe's findings (1985) note that while women were able to entertain the possibility that motherhood could be achieved without a biological relationship, the men defined their relationship to their child according to the part they played in the conception. Hence these married men continued to have extramarital relationships motivated by a desire to father children through the part they played in conception. The loss of a significant relationship is often an unspoken fear for many infertile couples (Mahlstedt, 1985:337). It also points to a woman's perception of motherhood as an integral part of marriage. The fact that the men chose not to leave their wives, but to continue with treatment may well reflect a similar belief to that of their wives.

The in-depth interview provided these couples with a safe place to verbalise these real fears. Shapiro as

quoted in Valentine (1986:66) notes that the infertile partner often encourages the fertile partner, either directly or indirectly, to seek a partner with whom he can have a child. This may serve to explain why women remained in marriages where they were aware that their husbands were attempting to bear children outside the marital union.

It also bears testimony to the amount of guilt these women experienced that made them believe that they did not have a right to forbid such relations. It is also possible that the social and cultural expectations inhibited these women from taking a stand by terminating the marriage. Thus women who did not meet the cultural expectation of motherhood, ran the risk of losing their most basic identity. In certain cultures, intelligence and creativity are secondary valued goals which women in society are socialized to strive for. Sociologist, Barbara Katz Rothman as quoted in Hoffman Baruch et al, (1987:81) notes that:

> Lacking economic power, physical and emotional safety, women can be coerced into motherhood, which seems to offer a power base from which to negotiate some degree of status.

In South African society the power relations of women have been both institutionally and culturally robbed. The sample reflects the educational qualifications of women who lack freedom, as a function of their limited access to educational and employment opportunities. Women are socialised towards dependence, submissiveness and achievement through others by way of marriage and childrearing. Women strive to retain their power base through their role as mother. Having

children would ameliorate the sense of difference and stigma which the individual and/or couple experiences. It is well known that those couples who do not experience parenthood often experience themselves cut off from the nexus of motherhood and social relationships. Parenthood thus facilitates social integration and avoids a sense of stigma. Crowe (1985:550) finds that these infertile women overtly avoided topics which could lead to feelings of isolation, exclusion and difference.

Exploring alternatives

All couples interviewed were unanimous in their refusal to entertain adoption as an alternative to bearing their own child with the exception of one woman. This value partly explained the many years invested in infertility treatment. They chose a childless marriage above adoption. The literature findings abroad show that 35 percent of women and 19 percent of men were willing to entertain adoption as a viable alternative (Leiblum et al, 1987:172) In research carried out by Crowe (1885:549) finds that many women do not entertain the possibility of adoption because of long waiting lists. In this sense, In Vitro Fertilization can not be seen to be value neutral. The literature notes that In Vitro Fertilization reinforces the idea that one's own biological children are the only desirable structure of social relations between adults and young children (Crowe, 1985). IVF may well attract individuals whose value system reflects this view.

Some couples expressed a wish to open their home to a child born from an extended family member who was unable to financially care for the child. Raising

this child was seen as an option to fulfill their nurturing needs. It also implied that the biological component was less significant to a woman than the desire to nurture a child. This did not imply that a woman did not want to be deprived of the opportunity of experiencing pregnancy and childbirth.

One couple (C) raised the option of surrogacy as an alternative to childless couples, using the sperm and ovum of the infertile couple. This was more acceptable to this one couple than adoption as they viewed a child born of such a union as being part of their seed.

Financial considerations

The financial investment in the programme demanded that couples have enough money saved up to undergo a treatment cycle. The financial consideration was mentioned by couples B, D, F, I and H as the major criteria should they decide to discontinue treatment. Because of the costs involved, couples could not afford to undergo successive treatments over a short period of time, possibly increasing their chance of conception. Couples were thus forced to undergo a treatment and then wait for a significant period of time before the next treatment cycle could be afforded. This prolonged the years of infertility treatment and possibly could add to the couple's sense of not being in control of their world. The majority of husbands (6) and wives (6) believed that the treatment was financially worth it to them. Some husbands (2) and wives (3) were unsure.

Where financial constraints impacted on the couple's future options they needed the reassurance that they would not be excluded from future treatments. It was

therefore important for couples to be secure in the knowledge that the door would not be closed owing to financial constraints, and couples saw the counsellor as a person who could help them address these issues. The following extract highlights the impact of the financial considerations for the couple:

> The most difficult part of the programme is the financial - the reason why I am doing this why do I go through this when my husband is unemployed? Out of work for so long and my age is catching up on me. So I feel I have to cope. There are no jobs. He does nothing all day. It is very difficult for me to cope and it does affect our marriage (Wife in couple F).

Decision around discontinuing treatment

There appeared to be difficulty making the decision to discontinue treatment. One woman who had continued with treatment for more than ten years had done so because she expected the physician to indicate when treatment was no longer viable. In part this reflected the tendency to subjugate one's will to an authoritative figure expecting to be guided and directed towards future treatment and treatment options. Because the medical team were unaware of this view, they were unable to respond to it appropriately.

Van Hall (1985:318) notes that couples may pressurize doctors to continue with diagnostic tests and treatments which are often unnecessary. He believes that there comes a time when the gynaecologist should earnestly query who wants this baby, the doctor or the patient. "The gynaecologist should overcome his own

frustration, admit his inability, and direct his attention and energy to helping the couple to cope with their grief. Sometimes it is less painful to endure a negative certitude than a positive incertitude" (Van Hall, 1985:318).

Husbands relied heavily on their wives to exercise choice around subsequent treatments. Husbands were aware of the immense emotional and physical cost of a treatment programme such as this for their wives. This awareness, coupled with a need to protect their spouses from distress, was a significant reason expressed by husbands to discontinue the treatment option. Husbands noted that they would advise their wives to stop attempting to conceive if these women manifested physical distress over time. Physical distress was explained as "tiredness, listlessness or where she (my wife) feels that she has become weaker." This again highlights the need to treat infertility as a couple issue. Husbands can provide doctors and the team with valuable information regarding how they and their wives are coping.

Despite the above data, the qualitative data suggests that most of the couples (8) were prepared to try another treatment cycle; the remaining couple decided to withdraw from the programme. Reactions to an unsuccessful Test Tube Programme showed a wide variety of responses. The predominant response among husbands was that they were satisfied that they had tried the programme, followed by a feeling of sadness. For wives, the predominant feeling was that of sadness followed by satisfaction at having attempted the programme and a sense of being unfulfilled. Despite these findings, most of the respondents (5) believed that a subsequent attempt at the Test Tube Programme

would be as stressful as the first. The remaining couples (4) did not share this view. These findings correlate with those in the literature (Greenfield & Haseltine, 1986:124).

Previous infertility treatment

In terms of their gynaecological history none of the women had undergone a tubal pregnancy or artificial insemination by donor sperm. One woman had suffered a miscarriage. Two women had given birth to children in the past. The one woman who was married to a man who presented with an infertility problem, had given up her child for adoption when she was young and unmarried. The second woman had lost a child when the child was one year old. The current research did not show that women who had borne children were in any way less affected by their secondary infertility than were those women faced with primary infertility.

4.1 SECTION B: EXPERIENCE OF SERVICE DELIVERY

Language of brochures

The majority of patients had no difficulty understanding the medium in which the literature was given to them. Literature is available in both English and Afrikaans. The majority of patients (15) claimed they grasped the information given to them by the medical practitioner. The remainder (2) were unsure as to whether they fully understood the procedures. Because of the quantitative nature of this question it was not possible to ascertain the degree of the patients' understanding with any accuracy. Lack of appropriate terminology in African languages may complicate the writing of brochures however this could be attended to, although those interviewed did not feel this necessary.

Evaluation of medical service delivery

It is the clinic's policy that couples attend the initial session together. Most of the couples (8), on request of the physician, complied with this. Only one couple did not attend the initial interview together. Most couples (8) maintained that they felt comfortable asking questions during the doctor-patient consultation. One patient was unsure and another found it difficult to ask questions, explaining that the doctors were always in a hurry. Most couples felt at ease asking questions in a context that was conducive to it. Unfortunately, the frequency of the contact between patient and doctor was not adequate, thus minimizing the forum for patients to voice their concerns and ask questions. Despite this, eight husbands and nine wives answered positively to the question of whether enough time was given to them while on the programme. There was a 100 percent response rate affirming that patients understood the reasons why the clinic required both blood samples.

Gender as a variable

The majority of males (8) held that the gender of the staff member taking them to the semen room did not matter. This finding reflects the acceptance that is generated in the context of a hospital. The same statistics were forthcoming from the women interviewed.

4.2 SECTION C: EVALUATION OF FOLLOW-UP SERVICE AND TREATMENT

Evaluation of staff service delivery

The majority of couples (5) felt that when they questioned staff about matters relating to infertility, the staff adequately answered all their questions. The remainder (4) felt that most of their

questions were answered. Yet despite these findings the qualitative research points to a lack of adequate patient-staff involvement. In the qualitative research one couple (B) noted that it was important for the team to be aware of what the issues are confronting the couple, as "patients need more understanding." (Couple E) Another suggestion which came out of the qualitative data supporting more team involvement, was the need expressed by two couples (B and C) who felt that the team should follow up after the ovum transfer and the pregnancy test results.

> There were no follow-up calls. It felt like they forgot about me. And maybe they did. (Wife in couple C).

Husband involvement

All the wives felt comfortable when their husbands attended the clinic with them, even though their husbands were not always involved in the procedures. The majority of women (7) would have liked the option of their husbands to be present during procedures and felt comfortable with their husbands' presence. Two women preferred their husbands not to be present.

Time allotment for patients

Most female patients (6) felt that sufficient time was allotted to them. Others (2) felt unsure and one felt that insufficient time was forthcoming from the staff.

Personal vs telephonic contact with pregnancy results

Most husbands (5) and wives (6) wished to be informed of the pregnancy results in person. The remaining husbands (3) and wives (3) wished to be informed telephonically. The telephonic response reflected the urgency of wanting to hear test results. "In person"

response was rationalised in terms of the information being traumatic. It raised many questions for the couple with no one there to answer them. Disappointment and sadness were the two dominant emotions mentioned at the time of receiving the negative test results.

Team Involvement at the Time of Pregnancy Results

There was a mixed response to the role of the team at a crisis point such as this in the fertility treatment. The majority of patients felt that the staff could have been more useful at the time. Only in one instance did a patient experience a team member reaching out to her and this encounter was self initiated. Team members need to be sensitive to the plight of infertility patients in order to respond in a comforting manner. The literature supports the notion that every staff member of a reproductive biology unit should become involved and familiar with psychological, ethical, and legal issues pertaining to infertility (Berger, 1977:145). It is interesting that the men wanted more team involvement than their wives. This could be related to their expressed feelings of exclusion.

4.3 SECTION D:

Evaluation of service delivery at the clinic

The majority of patients experienced the clinic staff as pleasant with only one patient experiencing the clinic staff as warm and friendly.

All patients felt confident regarding the confidentiality factor. Others saw the need for information to be shared within the team and had no problem accepting this.

No objections to the programme were posed on religious grounds. Most of the women (8) maintained that they experienced no objection to any particular part of the programme. One woman objected to being sent to a dietician.

Patient perception in retrospect

Responses indicate that there is no typical In Vitro Fertilization couple. Couples have a wide range of responses. Their level of apprehension and all their emotional responses are accentuated during their involvement with IVF-ET. Unless an opportunity is provided for them to work through these problems, they may well face some sort of emotional disintegration. All the patients on the programme were desperate for information of any sort and as such, this could have been in the form of explanatory notes and pamphlets, newsletters, videotapes, and group discussions (Johnston et al, 1988:500).

Suggestion box

All respondents held that it would have been useful if there was a suggestion box at the clinic where patients could have made suggestions to the staff regarding the treatment programme. This finding may indicate any number of the following:

- Patients may have had a need to assert themselves in a structure that tended to minimize the autonomy of the patients.
- Patients may have had realistic concerns or queries which they did not feel comfortable sharing with staff.
- Patients may have felt more comfortable with the anonymity of requests.

- This could have been the only way patients could realistically have had themselves heard by busy team members, who could then have responded to patients at a later stage. It placed the accountability on the team to respond to the requests. It would have been useful to have explored this issue further.

4.4 SECTION E: IMPACT OF THE TREATMENT

Impact on the marriage

From the quantitative data this was not ascertained. The qualitative research did hint at changes which couples experienced with regard to sexual functioning. Noticeably improved were the areas of sensitivity to the partner's feelings, an increased sense of closeness and sexual satisfaction. These findings are supported in the literature (Leiblum et al, 1987). Partners were often not in agreement regarding increased sexual functioning. Most affirmatives were mentioned by wives and not by husbands.

Reactions to the administration of pergonal injections varied. The most commonly sited side effect was weight gain, followed by abdominal discomfort and a feeling of being upset. Fatigue featured more prominently as a side affect in the foreign research (Leiblum et al, 1987:170).

4.5 FINDINGS RELATED TO THE INTERVIEW SCHEDULE

Informed clientele

Only one couple (C) attended an infertility clinic where counselling was offered prior to treatment, during treatment and after treatment terminated. This was experienced as invaluable because issues were addressed, misconceptions dealt with, questions asked and answers given in a supportive context. Not all couples expressed displeasure at the level of

information provided. The above finding is supported in the literature (Steptoe, 1985).

Most patients' anxieties were due to lack of information. It is essential that patients be fully informed of the details of the procedure, to be clear about its goals, and to agree to sign consent forms containing all necessary information. This must be done before treatment begins. Patients should not have to make sudden decisions in relation to their management if this can possibly be avoided. (Steptoe, 1985:489)

Questions emanating from this initial contact with the doctor triggered questions over time. However, for a number of reasons these were not addressed. Patients did not always feel comfortable verbalising their confusion. This was compounded by there being no formalised avenue whereby doctor-patient issues could be addressed other than in the initial consultation. Patients noted that doctors were unaware of whom they were talking to when explaining procedures. Thus, information imparted was done at a level which often added to the patients' confusion. Because patients experienced the medical team as distant this alternate avenue was not being fully utilized as a source of information and support. As a result patients tended to obtain support and information or misinformation in the "passage talk".

Who is the client

Rutledge (1979:257) notes that it is important for any work done in the field of infertility or marriage counselling to view the marital relationship as a triangular entity. The triad consists of the male in one corner, the female in the other and the marital

relationship in the third. In this way the individual separateness and the interaction of the couple is highlighted. Rutledge (1979) notes that the combined approach is imperative in order to remedy the role of stress in producing or contributing to male-female infertility. This approach addresses the stress component which may impinge on either the individual or the couple, affecting their interaction. It is important to have an understanding of the marital interaction to assist the couple in reducing stress, thereby facilitating the individuals to be better able to support one another during and after the treatment protocol. It is therefore important to address infertility as a couple issue, as is illustrated in an extract from the qualitative data.

> The problem is a problem for the couple. It is my problem because it is my body. It is my husband's problem financially. It affects both of us in different ways. For example, my husband producing sperm - it is not just a natural thing. I think my husband felt excluded on the programme (Wife in couple F).

All couples interviewed felt that they were acknowledged and treated as a couple. The request by the attending physician to attend the initial consultation together with the couple was experienced as confirmation of this opinion. It was the lack of frequency of these contacts that was missing. However, when it came to participation, various constraints operated. Husbands who worked were not always able to make themselves available, although every concerted effort was made by all the spouses to accompany their wives to the "major procedures" such as ovum pick up. Two husbands on the programme who

were unemployed, found it easier to meet the demands of the programme as they were not limited by time constraints.

Stressful points for men: sperm donation and ovum pick up.

Husbands endorsed the idea that infertility should be addressed as a couple issue. These husbands did not want their involvement to be limited to sperm donation. These men requested to be more involved, especially at the ovum pick up. During the ovum pick up, attention was focused on the wife and the needs of the husband were not acknowledged and therefore left unaddressed. Husbands would have liked support, feedback and information at times such as these in order to facilitate their sense of involvement in the infertility protocol. This following extract illustrates the subjective experience of a husband who did not feel involved or supported during a major procedure.

> I accompanied her to certain points of the procedure. Then I am left to wait outside during the ovum pick up. I do not know what is taking place and how many eggs they are going to come up with. They don't tell you straight. Nurses come in and out. Doctors are just doing their thing taking off their clothes (surgical gowns) and then just leave you. Doctors should talk to you (the husband). Some are talkative and they like to explain. Other doctors do not see why they need to explain. Husbands need to be acknowledged and we want feedback (Husband in couple H).

The above quote reflects the medical team's tendency to focus on the medical issues to the exclusion of the psychological issues. The emphasis needs to shift to acknowledge that both infertility and the programme have a profound impact on the psychological lives of the individuals whose lives it touches. Involvement mitigates against anxiety. There may well be realistic constraints why a husband may not be able to accompany his wife to certain procedures. While many husbands may not desire this involvement, it is the issue of choice of involvement that is important. This would have eliminated the feeling of exclusion. It is possible that the feeling of exclusion is symbolic of the husbands being excluded from the physical act of procreation, and that being part of the procedure in some way compensates for the sense of non involvement. Clearly husbands saw themselves as being affected by their wives' infertility and subsequent treatment. Husbands also wished the team to address the reality that they did not share the view that infertility was their wives' problem. This was encapsulated in the following quotes :

> If they would call you in together and say, "look here we are going to exclude you for this reason," then it is okay. But not necessarily that it is only the woman's problem (Husband in couple C).

Expectation on the programme

Mahlstedt (1985) attributes the marked stress experienced by these couples to the numerous simultaneous and complex losses which the individuals were forced to confront. Because there are no avenues to mourn this loss stress experiences are intense. Mahlstedt also notes

that because infertility is a major life event which requires change for couples with a prolonged series of "hassles" it is particularly stressful. Individuals ability to tolerate stress varies. "A person's confidence in his or her ability to handle stressful situations is a major factor in determining the severity of the stress" (Burns, 1988:30). The stress is both physical and emotional. The physical and emotional expectations of the couple concerning the programme varied. Five couples (C,A,E,F,H,) found the programme more stressful on a physical level than expected.

Thus there is an adaptation to the stress over time as the unfamiliar becomes familiar.

The sexual act

On a physical level men experienced the sexual act and semen donation as difficult for them. Childless couples may experience infertility as jeopardizing their individual sexual indentities. Fertility and virility are closely intertwined. The loss of sexual spontaneity was evident in couples who underwent this treatment programme. In keeping with the literature's findings, constant intrusion into the most intimate aspects of couples' sex lives caused them to feel a violation of a deep sense of privacy (Mahlstedt, 1985:337). Lack of appropriate guidance around sexual issues on a programme such as IVF-ET often left couples bewildered as is illustrated in the following extract:

> Our sexual habits changed. We were psychologically affected and therefore our sexual habits were affected. Whether frequency increased or decreased, its (sexual

> life) affected. I think it differs from person to person. You are scared because you have to perform in some cases. That you should be doing it (sex) or not be doing it or it (sex) ... is it the wrong timing. Sometimes you just don't have the need. Sometimes I feel that I should be doing it. I need information to know whether I can loosen it (ovum). We were told not to have intercourse after the implant. We did not know for how long and why. The conclusion I came to is that up to now I still am not sure. Is it because I can affect the chances (of conception taking place) (Husband in couple C).

Thus the sexual act moves from the physical to the clinical. Sexual dysfunction as a result of infertility workup is acknowledged in the literature (Sapire,1986; Leiblum et al,1987; Dennerstein & Morse,1985). One wife (B) felt that it was important to provide the men on the programme with, "more guidelines regarding the intimate parts of the marriage".

<u>Donating semen</u>

The importance of providing couples with an appropriate facility for semen donation is illustrated in the following quote:

> It would have helped to have a proper facility and to take her (the wife) in. If it were possible to produce the sperm twelve hours before and to freeze it. This would take the stress off the husband. He can then

> be more available to his wife (Husband in couple E).

The facility provided at the hospital consisted of a small room, not large enough for a partners to accompany his spouse should the wife have wished to assist her husband. The facility was stark and clinical. This lack of sensitivity was the cause of much distress experienced by men. The act of semen donation needs to be viewed with sensitivity especially across cultural lines. Semen donation was experienced as stressful for both husband and wife where it was not culturally sanctioned as is illustrated below:

> Men are not so involved. Just the specimen - it was very difficult for him to produce semen with masturbation. Masturbation is foreign to him. He told me that he had not even done it as a young boy. He told me he does not like it. Very bad. Stressful. It took him almost an hour. I was with him and had to help him. Even before (producing semen) he did not want to hear (about having to produce semen) (Wife in couple F).

One patient commented on how she experienced difficulty navigating the structural facilities of the hospital.

> Because physically you are seen at one end of the hospital and blood given at another. I am fortunate that I do not work. The facilities should really be in one block. Sometimes you are seen on one side for blood and they keep you waiting. Then you arrive

> at the other end late. It is not my fault that I am late - even if I plan it (Female in couple C).

The emotional impact of the programme

Couples were more particular regarding the emotional impact of the treatment. The most stressful emotional times for women were the pregnancy results, followed by semen production and return of menses. For men the most stressful periods consisted of semen production followed by pregnancy results and return of menses. In the qualitative data all female respondents on the programme complained of mood swings while on the treatment cycles. Three husbands (E,F,J) noted that it was difficult for them to deal with these mood swings. This affected them personally as well as a couple, as is illustrated in the following quote:

> We need to protect each other. The roller coaster affect of infertility was difficult. Sometimes she is up and sometimes she is down. It can happen over an eight hour period. It changes from morning to night. She seems to go from hope to despair (Husband in couple C)

Husbands found these mood swings particularly difficult to handle. Hope and an ability to adapt to stress were the two factors mentioned which aided them in coping with the demands of this stressful protocol.

Support

Support obtained through sharing an infertility diagnosis with a significant other proved to be useful to couples. Husbands were less likely to share their infertility diagnosis compared to the wives on the

programme. In order of preference individuals most often turned to their friends (9), followed by mother (6), father (5), employer (4), father-in-law (3), and in two instances individuals confided in siblings. Confiding in a sister-in-law (1) or the clergy (1) was rare. Secrecy and a desire for privacy was evident. One couple believed that it was a private affair, as is supported by the following extract:

> I have not told others. I regard this as very private. I choose to keep it private. I do not want people to laugh at me. It (the programme) is too stressful anyway. It (infertility) is just a joke to others anyway. I am very sensitive about it. Especially with women who have children. Women think that you are nothing if you don't have children (Wife in couple E).

The fear of disclosure through withholding of information was symptomatic of alienation and isolation intensified by infertility. It revealed the wish to be understood and the fear that it was impossible (Goodman & Rothman, 1984). This is illustrated in the following quote:

> We speak to friends on a different level. I size you up and take you so far. (Husband in couple A).

The more comfortable people were with their own infertility, the more likely they were to share this information with others. Others were more selective in whom they confided. Employers were informed to facilitate time off work. The findings are supported by the fact that the person chosen to confide in was

chosen in order to offer support, or withheld out of a desire to keep the protocol a private matter (Haseltine et al, 1985:510).

In response to the question, who the respondents turned to in time of stress, it was noted that they most frequently turned to their spouse, followed by themselves, friends and others. It is the secrecy, the shame and the privacy which motivates these couples not to reach out. Through so doing they become more isolated in their suffering and the marital dyad is more at risk in terms of containing the stress induced by the condition of infertility

Support systems remained vital for infertility patients as a way of coping. Open communication between couples and sensitivity to the spouse's feeling was essential in buffering the emotional impact that the treatment protocol engendered. Support could be forthcoming in various forms, whether through counselling, friends or a member of the team. Because the medical practitioner and the team had the most frequent contact with patients, it is important that these individuals were aware of the psychological components facing couples. The supportive and informed stance would prove to be in the best interests of patients (Mahlstedt, 1985:335). The kind of support couples desired tended to be individualistic.

None of the husbands or wives were involved in any sort of counselling during the treatment period. Most husbands (7) and wives (6) thought it advisable for a counsellor to be made available to each couple while undergoing the treatment. Those husbands (1) and wives (2) who were reluctant to utilise a facility

such as this, were in the minority. All the wives (9) and most of the husbands (6) maintained that they would have made use of a counsellor if he/she were made available to them during the treatment programme. These figures indicate a perceived need for counselling by couples with a willingness to utilize a facility such as this were it to be made available. These statistics also reflect the extent to which psychological needs were not attended to on the protocol. The need for counselling and supportive psychotherapy in an infertility clinic is well documented in the literature (Berger, 1977; Bresnick & Taymor, 1979), and was strongly voiced by respondents in this study. Women are generally more affected than their male counterparts. However, males were affected and they too benefitted from counselling (Bresnick & Taymor, 1979:156). The value of social work involvement at the outset of treatment has been found to be a useful time to help couples dispel any ambivalence towards the treatment. It was also a useful time to determine whether couples were willing to pay both the emotional and financial price of such a procedure, with no assurance of success (Needleman, 1987:141).

Sharing the information related to infertility helped diminish their sense of aloneness, and provided a place where feelings regarding their sense of isolation from the outside world could have been verbalised. Often the need for privacy proved to be a strain, especially for couples who lived in an extended family system, as is illustrated in the following extract:

> I would not tell anyone (about the infertility) if she did not tell. We would

> have liked to have been more open with our family. We sneak out and they don't know where we are going (Husband in couple E).

Infertility can be destructive to the couples' interpersonal relationships with family and friends. The need for secrecy may often be an attempt to hide shame (Goodman and Rothman, 1984). This same woman felt that various important issues could be raised in counselling. Issues of concern to her were to work through the pain of infertility and for the counsellor to explore with the couple how the infertility affected them on both an individual and a couple level. She also saw the counsellor as the concerned person who would enquire after the treatment procedures to query how well it went and to monitor her emotional state. Not all couples felt the need to confide in a counsellor. Some couples found this intrusive although these were in the minority. Despite differing views held by these couples they nevertheless acknowledged that other couples may utilize such a facility. Some couples felt that a counselling group would have been helpful to addressed the problem as a couple issue. This is supported in the literature (Goodman & Rothman, 1984). Goodman and Rothman (1984) note that group support serves to increase patients' energy levels, hopefulness, alleviate depression and address the emotional needs of the patients. Groups also serve to increase patients' knowledge of infertility, reduce their isolation and replenish some of the womens' self esteem. The group experience is useful in addressing the negative feelings infertile couples have towards family and friends. It thus serves to facilitate their social integration.

One woman (F) felt that counselling afforded the individual an opportunity to obtain more information regarding the programme, obtain support on an emotional level, and deal with the marital issues confronting her. This woman's husband remained uninvolved throughout, leaving her with a lesser level of marital satisfaction and life contentment which is substantiated in the literature on women whose husbands remain uninvolved (Links & Darling, 1986:57). The team were also unaware of his unemployment and the effect it was having on his wife's stress levels, highlighting the need for ongoing assessments.

Example:

> We would like to share but who can you talk to, who can you trust? There should be a counsellor. It would make women feel better. It is very traumatic to go through this, especially for women. The long wait and no-one to talk to. Its like hell (Wife in couple E).

The above quote supports the literatures' findings that infertility is in many incidences a social event as opposed to a purely physiological event (Menning, 1977). It also highlights the immense emotional load which these individuals are left to carry because no facility is provided to address the psychological issues accompanying infertility and its treatment. Individuals often experience guilt surrounding infertility, and counselling provides a useful avenue to explore these issues. One woman's unaddressed guilt related to her promiscuous past and the belief that this contributed to the infertility problem, as is illustrated in the following extract:

> Personally, I blame contraception. Parents don't understand about contraception so we (young girls) had no one to tell us what is happening. I experience guilt that the infection (which blocked or scarred her fallopian tubes) came from being promiscuous and uninformed. For the past three years this has bothered me (Wife in couple F).

Mahlstedt (1985) notes that guilt is also a futile attempt to gain control over the question "why" as is illustrated in the above quote. It is believed that if the infertility is understandable, the individual would feel less depressed, less frustrated and less angry. This woman's comments reflect the point put forward in the literature that the medical profession have also lost sight of the preventive stance which should be taken in combating various contributing variables. These include poor health care, nutrition and environmental factors. Medical science must become more women-centred. The focus should be on what would serve women best (Spallone, 1989:31). Guilt was more prominent in the infertile partners in the relationship as is illustrated in the following quote:

> I didn't think he feels the emptiness I feel. He has a child. For me the loss is greater. Women always feel in a case like this that they are to blame (Wife in couple C)

Fertile and infertile partners

The medical evaluation sought to identify with whom the infertile problem lay. In whichever way these questions were answered, what was evident

was that the diagnosis created tension for the individuals involved. Goodman and Rothman (1984) note that often couples find these feelings so ambivalent that they overcompensate by repressing conflictual attitudes and ambivalence towards their spouses in order restore their marital unity. Where the infertile partner was the male, the wife socially accepted the role of the infertile partner out of a need to protect her husband. She had borne a child prior to the marriage which she had given up for adoption. It is possible that she was more comfortable with an admission of secondary infertility. This wife explained her stance as follows:

> I felt protective towards him. If someone I would say there is something wrong with me. I wouldn't tell people it is him. (Wife in couple A)

Crowe (1985) notes that given the choice, women prefer infertility to be their problem. This woman owns the problem as a function of a protective stance towards her husband. He in turn allows her to own the problem. In other instances not having a child was seen as creating social barriers for the couple. The wife in couple E noted that she felt as the infertile partner a "sense of emptiness, loneliness and very much rejected by her social circle."

The wife in couple F noted that she was grateful that her husband was not abusive towards her because of her infertility status. She had seen other husbands ridicule their wives when they could not conceive. Only one wife (H) who was infertile maintained that

she did not feel guilty being the infertile partner in the relationship because she knew that her husband's love for her was not dependent on her bearing children. It was also apparent that the infertile partner could sit with feelings of failure. The wife in couple B noted that being the infertile partner made her feel as if something was wrong with her body. There was a sense of betrayal by her body which she found painful to accept.

Fertile partners also needed to underplay their fertility because it became such an issue in the marriage. Fertile partners carried less psychic pain in their marriages. Fertile partners could be divided into those who had children from a previous relationship and those who had never borne children. Men who had never fathered (A,D,E,F,G and I) children found it more difficult than men who had (B,C, and H) fathered children.

All fertile partners agreed that most of the pain was carried by the infertile partner in the relationship. However, the fertile partner was under a different form of stress in watching the pain experienced by the infertile partner. The infertile partners in the marriage were particularly vulnerable. This was especially so when the spouse had children from a previous marriage:

> Wife: I do not think that he feels the emptiness that I feel. He has a child. The loss for me is greater. Both of us have not started at nil. He has plus one. Women will always feel in a case like this that they are to blame.

Husband: It's there all the time. We will not let this split us up. We will discuss it. It is part and parcel of life. I do not say that it is because you wore too short minis that you got an infection. It is not throwing out things that she can not answer for. I accept it because it is not her fault.
Wife: Not that it is not my fault. I can't help it. (Couple C)

Those couples who were able to adapt to their infertility in a healthy way were able to support each other despite the pain around the issue of infertility. This couple differed from the others in that their infertility diagnosis was known to them prior to their marriage. They both shared a healthy self esteem which was not evident in any of the other couples interviewed on the programme.

Husband: We will keep the marriage going no matter what. I do not believe in divorce.
Wife: Is it divorce or in leaving me?
Husband: We depend too much on each other.
Wife: What about love?
Husband: Involvement is love. We have come so far pulling this life together. If there is no love then you have built it up for self gain. Love keeps it (the marriage) together (Couple C).

4.6 Conclusion

The findings need to be seen in their appropriate context. The findings reflect the views of a selected group of couples given a specific context and receiving a specialized treatment option. The size of the sample mitigates against generalizations being

drawn. Each couples' experience of the psychological issues are unique and need to be addressed as such. A number of features stood out. Firstly, it was apparent that the emphasis in the treatment of infertility reflected a purely medical stance, with no attention being given to psychological factors. This was reflected in the lack of psychological screening of patients undergoing the programme as well as the lack of supportive therapy. As a function of this, many problems which were stress inducing were left unaddressed further adding to the patients' existing stress levels endemic to the protocol.

Patients voiced the need to have access to a counsellor during the treatment protocol. Their needs for a counsellor varied, ranging from an educative role to that of individual and marital issues. Most important was the fact that at no point in their infertility history did the patients have an avenue through which they could express their grief at a potential loss. Couples were further selective in sharing their infertility with selected individuals, thereby minimizing their support. This placed the marital relationship under particular strain as couples relied heavily on spouses whose unresolved pain had not been addressed to reach out to them. The pain tended to be more marked amongst the infertile partner in the marriage. The isolation of these couples was both evident in the marriage and in the larger community. The social pressures to have children were experienced by all the couples. However, what was particularly interesting was the level of commitment to their marriages and to bear a child from that particular union. The lack of entertaining alternatives to infertility were markedly lacking in the sample.

The area of service delivery patients appeared to be accepting of, was the structural limitation inherent in a hospital setting. Patients were appreciative of a facility which allowed them to regain a sense of control over their lives through the seeking of medical treatment. Patients did not take the initiative to alert staff to issues or to request information regarding procedures when confused. The staff, while experienced as helpful were not seen as approachable. Those couples who had infrequent contact with the physician were left with no avenues to explore concerns. Physicians and the team continued to treat infertility as a medical issue. The couples expressed a strong desire for the medical profession to mirror their belief that this was a couple issue and not an individual issue. Husbands tended to feel excluded from procedures and the importance of support for the fertile partner was evident, especially during periods when treatment procedures were being carried out on the infertile partner. The most stressful times for couples appeared to be centred around the ovum pick up; the period before the return of menses and the onset of menses. A lack of follow-up after a failed treatment cycle meant that treatment options were not being explored and no avenue was provided for exploring future treatment options, or looking at termination of treatment. The time constraints and structure of a hospital setting is not conducive to personalized treatment.

Infertile women in the sample felt vulnerable in the marriage as long as they remained childless. The majority of the women did not work. Not having an area in their lives where alternate validation could

be sought, they appeared bereft of their power base both in the marriage and in relation to their standing in the community.

Infertility can thus be viewed as a couple issue facing two individuals with differing needs going through the treatment at a different pace. The sociological forces which drive men and women to parenthood may have similarities. However, there were enough significant individual issues to realize that the impact of infertility was highly subjective, even though similar themes existed.

CHAPTER FIVE: RECOMMENDATIONS

In this chapter recommendations based on the findings will be made.

5.0 Screening and Counselling

There is a need for the assessment and structured management of patients' psychological status in the same way as is presently provided for in their physical functioning. This can be addressed in any one of the following ways depending on staff availability and funding. Solutions cannot be imposed on autonomous systems. The current structure is unable to fund a clinician on the staff to provide a purely therapeutic service. This being the reality, it is important to explore what alternatives are available to the team given the limitations of the structure. If funding were available a clinically trained individual should address the psychological issues facing couples on the programme. The clinician's function should be multidimensional including the task of screening patients prior to admission to the treatment protocol. This would focus on screening out-patients at risk; address the means whereby couples handle conflict and stress; assess such factors as ambivalence, anxiety and unrealistic expectations of either partners in relation to parenthood and the protocol. Should psychological tests be used for screening purposes, this should be done with due consideration. Once the screening is completed a team decision should be made as to the couple's acceptability onto the programme. This will restore the central role of the team in decision making and simultaneously allow for the implementation of the recognition of the importance of screening patients for the IVF-ET protocol. The clinical social

worker should identify the stress points of the programme and provide a guideline for service delivery that best serves to support the couples emotionally through the treatment protocol. Support for the couple is essential. This would involve an educational slant is an informed client system are less anxious. Pre-operative and post-operative counselling should be available to address issues confronting couples. Stress reduction groups and relaxation exercises are useful coping techniques for couples undergoing the protocol. The clinical social worker should emphasize the use of the various coping strategies which could be utilized while on the IVF-ET programme. Griefwork should be ongoing as couples are helped to address the many individual and social losses which infertility creates for them. Failed cycles should be viewed as an opportunity to help couples address their grief and to make informed decisions regarding future treatment options or alternative routes to motherhood. At all times therapeutic intervention should be tailored to the individual needs of each couple. Should it not be possible to provide a clinically trained person to be part of the team the following suggestions are forthcoming.

Provision of supportive counselling for patients through alternate means would be helpful to them in alleviating their apparent emotional distress. Various options can be explored, among them: supportive counselling by a psychologically trained individual who forms part of the psychosocial team; referral to a support group; creation of a support group within the hospital context; the implementation of a buddy system; assigning one member of the psychosocial team to each couple entering the

programme, so as to minimize the distance felt between staff and patients. The rationale for the latter would be to ease the patient's sense of reticence regarding approaching a member of the team with concerns related to the treatment protocol.

Other functions of the clinician include playing an educative role in relation to the patients as well as the psychosocial team; assisting patients in dealing with the emotional stress generated at nodal stress points of the programme; and to create support groups if these are viable.

Should the funding mitigate against employing a full time member of staff, close liaison with the psychiatric department could be maintained in regard to screening and/or referral of couples who present with either individual or marital concerns. A representative from this department could be co-opted onto the psychosocial team and be available for consultation around concerns related to the patients. Representation of this nature facilitates a closer link between the psychiatric and infertility unit.

Staff education, regarding the psychosocial impact of infertility on the lives of the patients whom they are treating, is important. Team members should be encouraged to be more sensitive and supportive when dealing with patients. It is important that at least one member of the medical team be familiar with counselling. A treatment guideline could be implemented which reflects this stance. This role could effectively be carried out by the clinical social worker. Nursing staff should be educated not to be intrusive.

The accessibility of staff should be increased by telephonic availability. This may be in the form of a phone-in line specifically allocated to queries. The responsibility of responding to these calls may be allotted to specific members of the team. Where queries cannot be answered the relevant person would need to be contacted and could then respond to the informant.

To educate patients regarding treatment options, procedures and procedural side effects with the implicit goal of alleviating or minimizing the level of confusion and anxiety surrounding the operative procedures and requirements of the treatment protocol. An informed couple are better able to deal with a treatment protocol such as this.

Group service could be instituted to address the psychological loneliness and isolation suffered by these patients.

5.1 **The medical team's responsibility**

In order to avoid unnecessary prolonged treatment the following suggestions are made:

Large periods of time between treatments should be avoided. If possible, a few successive treatments should be implemented so as to ensure a higher probability of conception. Financial constraints may mitigate couples against continuing with treatment. Avoidance of prolonged treatment allows for both physician and the psychosocial team to make crucial decisions around alternate treatment options or, alternate means of parenthood.

Focusing on physical treatment at the cost of the emotional needs of these couples should be avoided. This implies that the body and the mind should be seen as inseparable and calls for a holistic treatment paradigm. The minimum goal should be to look at the impact of the physical treatment and to address this in various ways. Patients need additional literature and educative devices to make better sense of this complex treatment. A series of multidisciplinary talks relevant to the protocol could be given every twelve weeks. In addition patients need to be made aware of the various medical tests available and the reasons why these are carried out. The probability of success of the treatment should receive attention. Where treatment fails, couples need to be informed of the results in a joint interview. This is a fruitful time to listen to the feelings expressed by the couple and to offer emotional support. Other issues that need exploring at this session include:

- referral to a second expert opinion, if necessary.
- to explore what more could be done to alleviate infertility.
- to explore available alternatives should the couple discontinue treatment.
- to inform couples of existing community resources which could assist them. Test results should preferably not be given telephonically.
- the financial constraints of couples should be ascertained by both the physician and the counsellor so as to minimize realistic pressures facing these couples.
- to be alerted to symptoms of depression in couples which is a typical phenomenon

resulting from this lengthy treatment process of diagnosis and subsequent treatments.

Dealing with infertility as a woman's issue should be avoided. This calls for a recognition of infertility as a couples' issue. Joint meetings should be held with couples prior to treatment, before the ovum pick up, after the ovum pick up and upon the outcome of the treatment results. All attempts should be made to involve husbands in the treatment through emotional support and the option of being present at the various procedures.

Anxiety engendered through a protocol such as this should be minimized. This could be achieved through running stress reduction groups, relaxation groups, and a better educational input for patients in order to ensure that the client system is an informed one. Supportive work could alleviate the stress for both clients and the psyhosocial team. Patients need pre-operative and post-operative counselling by any member of the psychosocial team. Adequate support during the assessment and work up phase with subsequent weekly follow-up visits, up to and until discharge, is indicated in order to create space for individual and couple counselling.

Patients require a closer patient-doctor relationship throughout the protocol where concerns can be addressed, medical management queries raised, explanations obtained regarding treatment failure and alternative treatment options explored. Where possible patients should be seen by one doctor throughout the treatment programme.

Closer contact between patients and the team could serve a vital function in orientating patients to their current reality by providing them with input as requested and desired. Team members and physicians should talk to patients in a way that enables them to make sense of the complexity of the procedures and the reasons for failures. A possible suggestion is to assign a staff member to each couple. This will be the staff member whom the patients can contact with queries. It would require a formal introduction.

Team members need to be seen as more human. Photographs of each member in the corridors, with identifying particulars, may serve to minimize the distance existing between team members and patients. This would also serve to educate the patients regarding the different functions each member of staff fulfills.

Staff support groups may well be indicated to deal with the stress which the team members are placed under in a unit such as this.

Referral by a doctor or team member to other departments (dietician, psychiatry, sex therapist) needs to be handled with sensitivity.

The educational level of the patients may have an implication for the mode of educating patients. Complex information may be better imparted through audiovisual means. Existing written pamphlets may need modification to convey technical information in less medical jargon. Thus, the educational level has to be slanted to suit the sophistication of the population group serviced.

A booklet, in a response form which deals with questions and answers related to all possible concerns that would confront a couple undergoing a treatment option such as this, could be published.

5.2 Recommendations for future research

A follow-up study to ascertain how couples resolve their issues around infertility once they are no longer on the programme would be useful. This would provide an understanding of the psychological healing process which couples undergo who have come to terms with their infertility failure.

An explorative study into the role and needs of husbands in infertility would provide a guideline towards more effective supportive intervention.

Research needs to be done into the association between patients' anxiety levels and the outcome of treatment, as well as the long term impact of the programme on the couples' adjustment.

A comparative study is needed to note the differences between couples whose husbands are involved on the programme and those who are not.

A more in-depth look at the impact of the treatment programme on both husbands and wives on a systemic level should be undertaken.

The current study should be replicated on a larger level in order to evaluate what the dominant view is surrounding patients' needs in a unit such as this.

A retrospective analysis of the treatment by patients who choose to discontinue medical options.

CHAPTER SIX: CONCLUSION

Infertility exacts an immense burden on the individuals and couples whose lives it touches. Singled out from the mainstream of a transitional life event through an inability to conceive, the research highlights the unaddressed pain which these couples have experienced over years. IVF-ET does not cure infertility. IVF-ET is a medical response to a biopsychosocial challenge.
The stress confronting couples was largely attributed to the medical protocol and psychological implications of a treatment such as this to an involuntary childless couple.

Neither the context of a large hospital nor the training of those attending to the infertile couples, render a service delivery which reflects their acknowledgement that it is viewed as a biopsychosocial challenge. The impact of the treatment reverberates not only across doctor-patient relationships; it impacts on the team as well. In order to respond to the needs of this vocal group of patients, those attending to them need to be educated towards the psychological impact of infertility and this treatment modality on the patients' lives.

While the sample size mitigates against the generalization of the findings, results do point to the need to create avenues of communication to facilitate the educational input and supportive needs of patients and the psychosocial team. Most of the anxiety the programme generates was centred around major nodal procedures which couples underwent unsupported by the team or counsellor. Compounding this sense of isolation was the social isolation

confronting these couples. Their sense of privacy around this treatment modality negatively affected social support structures, leaving them more vulnerable and anxious. Years of unaddressed pain was present in the form of feelings of emptiness. The infertile partner tended to carry most of the pain. What the research did highlight was the stress confronting the fertile partner in such a union.

The major findings in terms of service delivery point to a need to address issues such as: lack of doctor-patient contact; inadequate communication between staff and patients; lack of adequate pre-and post-operative counselling; better preparation for an unsuccessful outcome; a lack of adequate screening and ongoing supportive intervention; inadequate facilities for sperm donation and lack of awareness and sensitivity towards the impact of a treatment option such as this on the biopsychosocial aspects of patients' lives. It is indicated that infertility be treated as a couple issue and to involve and support husbands wherever possible, thereby not treating infertility as a womens' issue. The isolation couples faced both socially and while on the programme, left them emotionally more at risk. Of concern was the fact that the team were unaware of the many psychosocial problems confronting the couple when ongoing assessments were not forthcoming.

Each individual and couples' experience of the treatment was uniquely subjective necessitating an individualistic stance to medical treatment and psychological intervention. However, all couples experienced difficulty around affording a treatment option such as this.

The research supports the idea that these individuals invest much in the outcome, and failure signifies for the individual and/or the couple, losses which are multifaceted, complex and often very painful. The qualitative research shows infertility is an issue about redefining the Self in the world; the meaning which the individual and/or couple ascribe to it, and the impact of this information which either propels individuals forward or holds them back.

As a treatment option, IVF-ET may serve to tap the core of mens'/womens' sexual identity. No longer being in control of their reproductive lives, it is important that the team attempt to involve these couples in procreation as much as possible. The procedures rob the sexual act of its potency and in turn leaves the men/women undergoing a programme like this, with diminished feelings of sexual prowess, control and virility. If it were possible to empower these individuals with a sense of control, a renewed sense of self-esteem and appropriate channels to work towards resolution of conflict and loss surrounding their infertility, much of the healing could take place. Of significance, too, was the richness of cultural factors in this study, and it is imperative that the attending team be sensitive to specific cultural issues. Given both financial and staff constraints in a hospital setting, the addressing of these findings require a shift in attitude towards service delivery. It requires the protocol to be viewed as a biopsychosocial challenge thereby demanding a more holistic medical service delivery.

APPENDIX A

Andrology
4046027/8

23.06.94

Dear Mr & Mrs

We are currently undertaking a research study on our test tube programme. The title of this study is "THE PATIENT SPEAKS: AN EVALUATION OF THE TEST TUBE PROGRAMME." This is being done by a Clinical Masters Student, University of Cape Town, under the supervision of the attending Physician. The student will evaluate the patient's experience of the test tube programme, exploring the nature of the service provided and to ascertain how patients cope with a programme such as this.

The assessment will involve interviewing each couple who has undergone the treatment starting from the month of June 1994. Interviewing times will be arranged after hours so as not to interfere with the couple's daily routines. Patient's responses will remain anonymous at all times. This means that reponses will be evaluated without disclosing your identity either towards the supervising physician or the lab team or anybody else.

Your participation is entirely voluntary. Whilst your participation would be appreciated your decision whether or not to participate will in no way affect future treatment at the clinic.

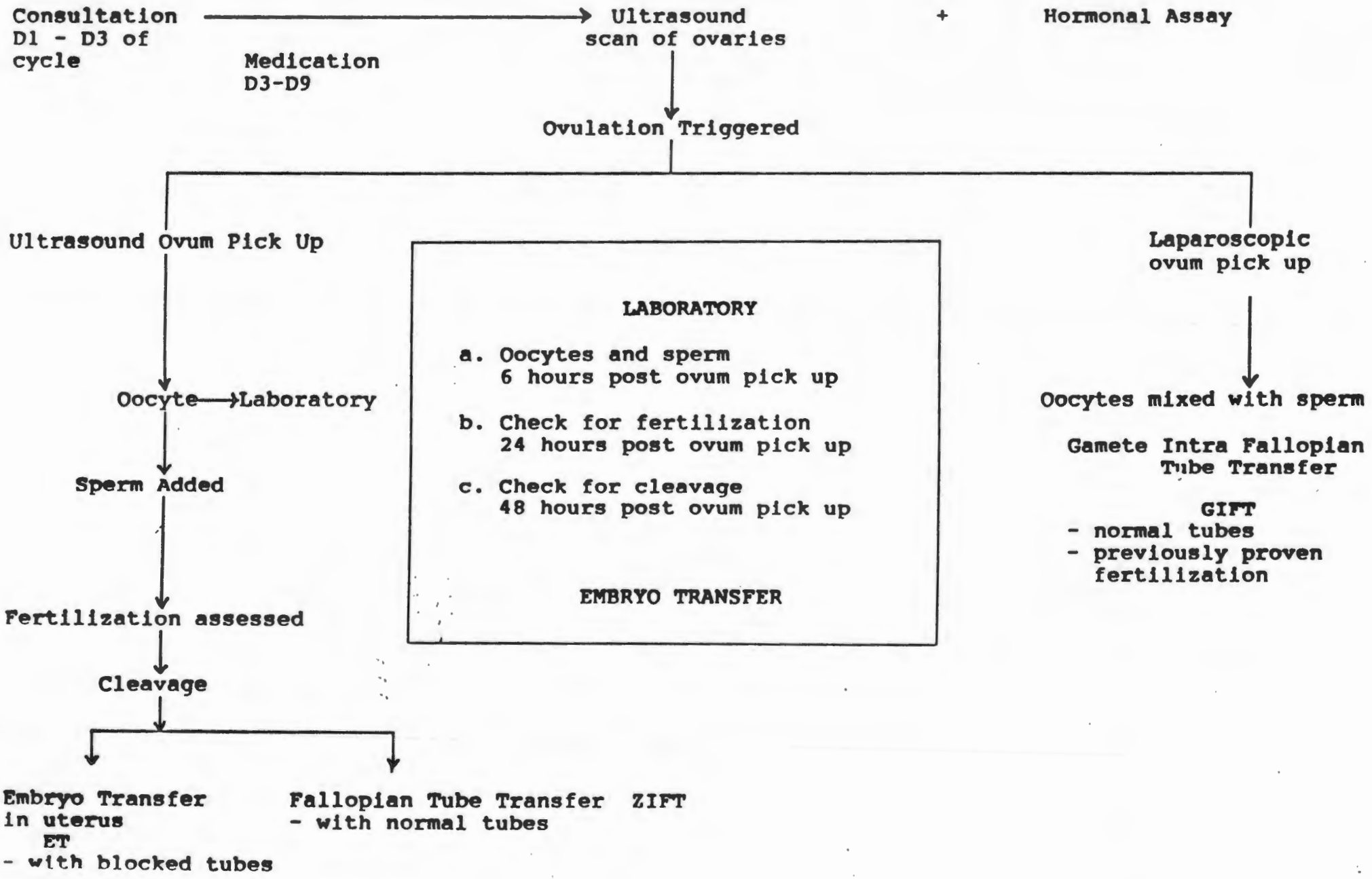
The purpose of the study is to evaluate patients specific needs on the test tube programme with the view of responding to this. Should you and your husband be willing to participate in this research, please inform the secreatry at the clinic at your earliest convenience. The research will hopefully be carried out from mid June 1994 - mid July 1994.

We thank you in anticipation.

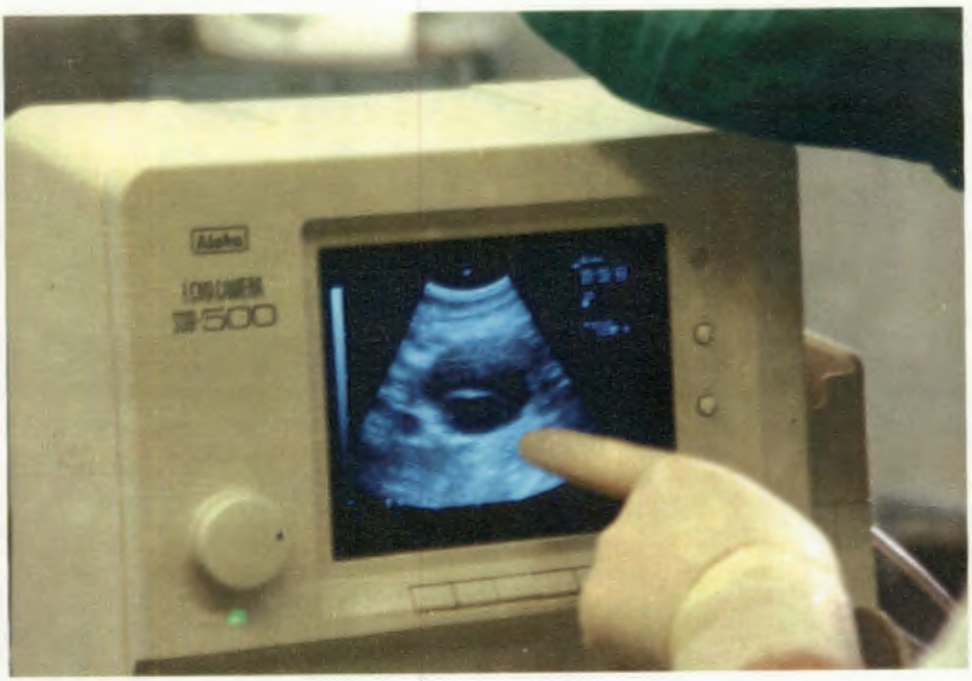
Yours faithfully

DR SILKE DYER

APPENDIX B

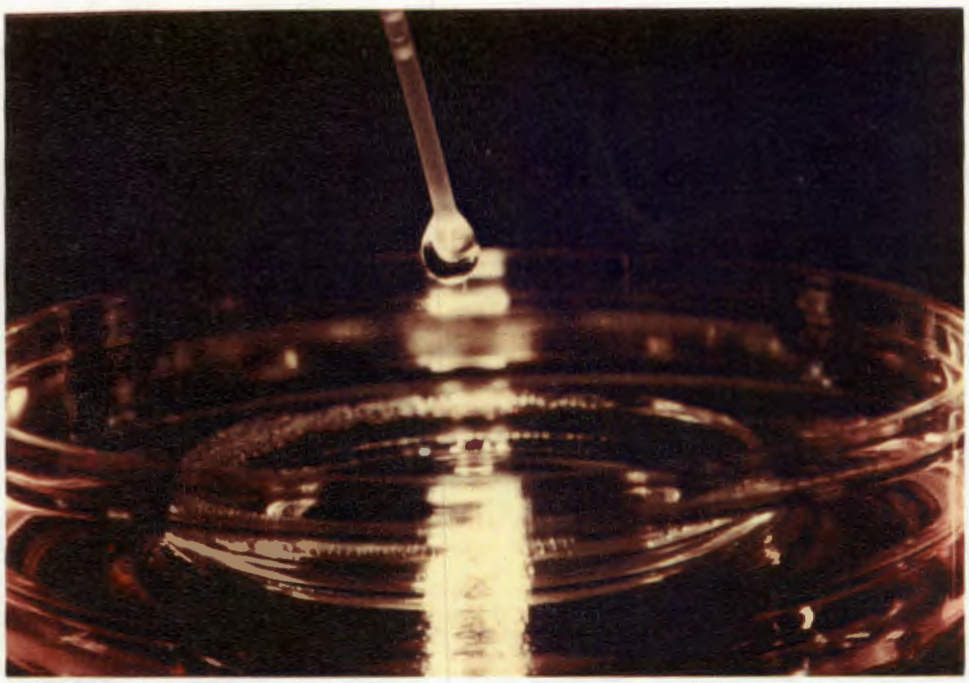

Consultation
D1 - D3 of
cycle
Medication
D3-D9
Ultrasound
scan of ovaries
+
Hormonal Assay
Ovulation Triggered
Ultrasound Ovum Pick Up
Laparoscopic
ovum pick up
Oocyte
Laboratory
LABORATORY
a. Oocytes and sperm
6 hours post ovum pick up
b. Check for fertilization
24 hours post ovum pick up
c. Check for cleavage
48 hours post ovum pick up
EMBRYO TRANSFER
Oocytes mixed with sperm
Gamete Intra Fallopian
Tube Transfer
GIFT
- normal tubes
- previously proven
fertilization
Sperm Added
Fertilization assessed
Cleavage
Embryo Transfer
in uterus
ET
- with blocked tubes
Fallopian Tube Transfer ZIFT
- with normal tubes

Laparoscopy ovum pick up



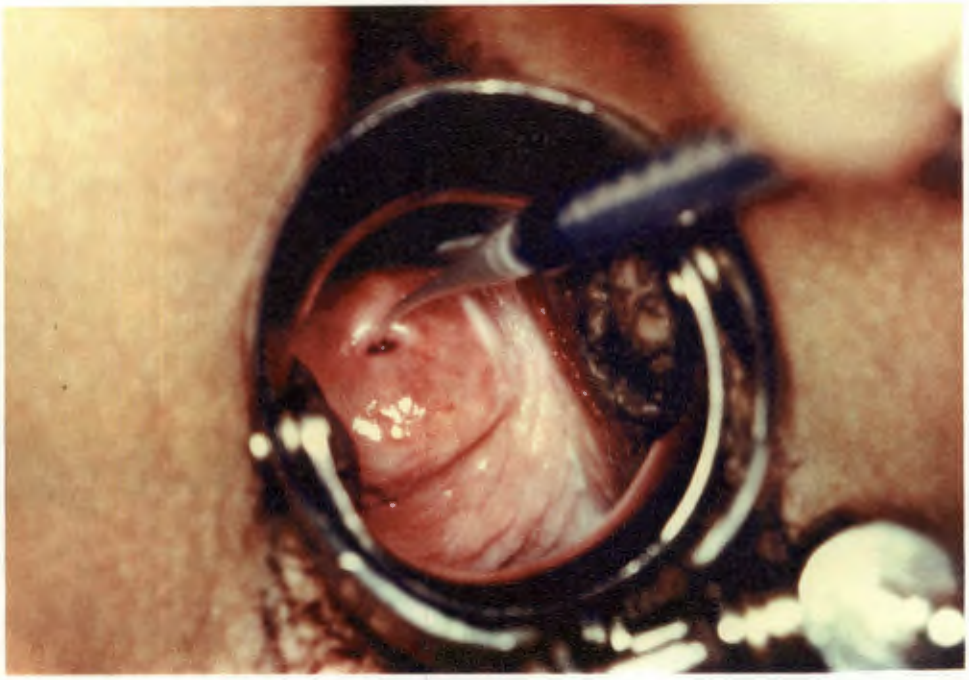
Visualization of follicles on sonar

Technician scanning for oocytes



Insemination of oocytes with sperm

Oocyte - embryo and culture in incubator



Vagina embryo transfer into uterus

Appendix D

MEDICAL INTERVENTION

Causes of Infertility

Male Causes

- Varicocele causes and chromosomal abnormalities.
- Inadequate sperm production.
- Structural defect.
- Poor ejaculation.
- Antibodies.
- Specific endocrine defects.

Female Causes

- Hormonal imbalance.
- Blockage.
- Mucus impermeable.
- Antibodies.

Options on the In Vitro fertilization programme

(see Appendix)

In IVF-ET the fertilised egg is allowed to develop further into an embryo over two or three days before being replaced, not into the fallopian tube but into the uterus (Test Tube Babies: A fact file on In Vitro Fertilisation).

The treatment process

Ovulation Induction

This stage concerns itself with ovulation induction. Fertility drugs are administered, usually on day three or four, so as to stimulate the growth follicles. Clomiphene Citrate and/or HMG (Human Chorionic Gonadotropin) are the drugs of choice to be administered on a regular basis to induce ovulation induction at the clinic involved in this research.

There are daily visits to the hospital from day eight or nine, enabling staff to administer ultrasound to gauge the number of follicles with the view to assessing the most appropriate time to do an ovum pick up. Blood tests are administered to monitor hormone levels. This occurs because the body hormone, luteinizing hormone (LH), consistently increases about thirty-six hours prior to ovulation. Blood test levels are important indicators which allow the medical to team determine the correct timing of the ovum pick up.

Ovum Pick Up and Laparoscopy

When the follicles have reached a desired size (18 - 20 cm) and good hormone production is detected, Human Chorionic Gonadotropin (HCG) is administered in the form of an injection. This serves to trigger ovulation and aids maturation of the eggs prior to ovum pick up which usually occurs 34-38 hours after the administration of the injection. Eggs are retrieved which requires a general anaesthetic, and the distension of the woman's abdomen with a carbon dioxide gas mixture. To remove the eggs small incisions are made below the woman's navel through which instruments are inserted. A laparoscope is a light guide which allows the surgeon to observe the ovaries. Forceps are used to grasp and rotate the ovaries while a suction device is used to retrieve eggs from the follicles. Trans Vaginal Ultrasound Directed Oocyte Recovery (TIDOR) is an alternate egg retrieval technique. It does not require a general anaesthetic and is less costly to use. A needle for retrieving mature eggs is inserted through the woman's vagina, into the bladder and toward the ovary. This procedure is guided by an ultrasound scan which guides the doctor in moving the needle around. Once the ova

are detected, they are retrieved and placed in a petri dish in a culture medium which contains salts and chemicals which are essential for the survival of the eggs outside the body. The eggs are then placed in an incubator which simulates bodily conditions. Fresh semen is collected from the patient's husband or sperm donor by masturbation shortly before the scheduled laparoscopy. The washed semen is then used for insemination with the eggs six hours after the ovum pick up.

Ovum Transfer

Fertilization can be detected 18 hours after insemination. Once fertilisation has taken place, life has effectively begun. The embryo continues to divide until it reaches a four cell division. At this stage the embryo is placed into the uterus through a painless procedure not requiring an anaesthetic. This is the simplest technical aspect of IVF-ET. The embryos are loaded into a fine plastic tube together with a tiny drop of culture fluid, to be inserted through the neck of the womb into the uterus, using a small syringe. The patient is required to rest lying down for four hours before she is allowed to return home.

Success Rates

Two different kinds of success rates are usually reported: pregnancy per egg retrieval procedure and pregnancy per patient having embryo transfer. Per patient success rate figures fail to reveal how many cycles the patient has undergone and is therefore deceptive. Success at any given clinic within a short time frame may also be misleading, especially when the success rates in the intervening months are not good. Patients stand an eight percent chance that the transferred embryo will cleave to the lining of the

uterus, resulting in a pregnancy. Ten days following transfer, blood tests are administered in order to ascertain whether or not the patient has conceived. The major determinant of pregnancy rates with IVF-ET is the number of embryos replaced in the uterus. Maximum results are achieved when three to four embryos are replaced. However, this will significantly affect the pregnancy rates as well as the number of multiple births. Pregnancy rates on IVF-ET are lower when this technique is used to overcome male infertility.

Cancellation of a cycle

Cycles are cancelled when the follicles are developing in an ovary which is not easily accessible; the number of follicles which have matured are too few; the blood oestrogen levels are too low to ensure the development of a healthy egg; the follicles may have ovulated prior to laparoscopy; ovarian cysts may have developed in response to the fertility drugs; and the division of the fertilised egg might not occur in an incubator. The two main factors involved in influencing the success rate are the quality of the embryos and the receptivity of the uterus.

* Medical information obtained from notes provided by the Groote Schuur hospital medical infertility unit.

APPENDIX E

FEMALE QUESTIONNAIRE

Date of birth_____
Date of marriage_____
Home language_____
Religion_____

Category A
Biographical data

1. Have you been previously married

Yes_____
No_____

2. Number of biological children

3. Number of stepchildren

4. Highest educational qualification

1. Std. 8 or lower_____
2. Std. 10_____
3. Diploma at Technikon / Technical college____
4. Diploma at teaching institution_____
5. University graduate_____
6. Other _____

5. From whom did you hear about the clinic?

1. Contacted the clinic yourself_____
2. Through family or friend_____
3. House doctor_____
4. Referred through another source(please specify_____

6. Have you undergone previous infertility treatment?

Yes_____
No_____

7. If yes, where have you received previous infertility treatment?

1. General practitioner
2. Private specialist
3. Infertility clinic

8. Is there a history of infertility in your family?

Yes
No

9. How long have you suspected that you have a problem with infertility?

1. Less than one year
2. One year
3. Two years
4. Longer (please specify)

10. What previous treatment have you sought to help you conceive?

1. Surgery
2. If yes, no. of procedures
3. Drug /hormone therapy

11. Have you ever been told the medical reason as to why you have had difficulty falling pregnant?

Yes
No

12. Which of the following diagnosis has the doctor explained to you as the medical condition you have which prevents you from conceiving?

1. Don't remember diagnosis
2. Haven't been told
3. Undiagnosed infertility
4. Blocked or scarred tubes
5. No fallopian tubes
6. Previous tubal ligation
7. Ovulation
8. Male problem
9. Endometriosis

13. What do you think caused you to have an infertility problem?

14. Have you experienced any of the following?

1. Miscarriage
2. Tubal pregnancy
3. Abortion
4. Artificial insemination with husbands sperm
5. Artificial insemination with donor sperm

15. How many treatment cycles have you attempted in the past? Please circle where applicable.

0 1 2 3 4 5 6 7 8 9

16. How optimistic were you regarding a pregnancy through the Test Tube Programme

1. Optimistic
2. Neutral
3. Skeptical
4. Varies
5. Don't Know

17. How well did you understand what would be involved in the treatment before you started ?

(1 = least understood to 10 = understood most)
Please place a cross over appropriate number.

1 2 3 4 5 6 7 8 9 10
Least Most

18. Have you told others about your participation on the programme?

Yes
No

19. If yes, whom have you told? Cross off as many as are applicable.

Mother
Father
Mother in law
Father in law
Siblings
Friends
Employer
Clergy
Other

20. If you have children, did you tell them?

No children
Did tell
Did not tell

21. How do you usually get through stressful times?

1. By myself
2. Depend on my spouse
3. Friends
4. Other

Category B
First interview

1. Could you follow the content of brochures given to you regarding the Test Tube Programme?

1. Easily
2. Adequately
3. Difficult to understand
4. Totally unclear

2. Was the language in which the brochures were written a problem for you to understand?

1. Not a problem
2. Quite a problem
3. Unsure
4. Difficult to understand
5. Totally unclear

3. Did you understand the procedures when explained to you by the doctor?

1. Understood
2. Unsure
3. Not understand
4. Totally unclear

4. Were you and your husband asked to attend the initial session together as a couple?

Yes
No

5. If no, would you have liked both husband and wife to be more involved in the procedures and in discussions with the doctor treating you?

Yes
No

6. Did you feel comfortable enough to ask questions during the session with the doctor?

1. Very comfortable
2. Could ask questions
3. Unsure
4. Would not ask
5. Did not feel comfortable

7. Did you understand why blood was taken from both partners?

1. Understood
2. Unsure
3. Did not understand

8. Did you understand why it was necessary to test your husband's sperm at the initial interview?

1. Easily understood
2. Not understood
3. Totally misunderstood

Category C
Follow up and treatment at the clinic is being evaluated.

1. When you questioned staff about matters concerning infertility, did you feel that your questions were adequately answered?

1. All questions
2. Most questions
3. Unsure
4. Not all questions
5. No questions

2. As a wife would you have felt comfortable if your husband attended the clinic with you, even though he was not always involved in the procedure?

1. 100% comfortable
2. Comfortable
3. Unsure
4. Uncomfortable
5. Totally uncomfortable

4. Would you have liked your husband to have been present at any of the procedures?
If yes, please specify.

Yes
No
Unsure

5. How did you as female feel talking to a male member of staff about matters relating to infertility?

1. Totally comfortable
2. Uncomfortable
3. Unsure
4. Uncomfortable
5. Totally uncomfortable

6. When attending the clinic did you feel that you were given enough time to discuss matters ?

1. Totally sufficient
2. Sufficient
3. Unsure
4. Insufficient
5. Totally insufficient

7. Which do you think is the better way to tell you of your test results, telephonically or in person?

Telephonically
In person

8. How did you respond when the results were told to you telephonically?

9. Could the staff have been more helpful to you at a time like this?

1. Definitely
2. Unsure
3. Definitely not

10. Were you involved in some sort of counselling during the treatment period?

1. Yes
2. No

11. Do you think it is advisable for a counsellor to be available to each couple while undergoing the treatment?

1. Definitely yes
2. Yes
3. Unsure
4. No
5. Definitely no

12. Could you make any recommendations regarding to the clinic's follow up procedure following ovum transfer?

Section D
Clinic's service delivery

1. How did you experience the atmosphere of the clinic?

1. Warm and friendly
2. Pleasant
3. Unsure
4. Unpleasant
5. Cold and impersonal

2. Did you believe that information given by you during the treatment was kept confidential?

1. Completely confidential
2. Confidential
3. Average
4. Not confidential

3. Do you prefer to be seen by one doctor throughout the treatment programme?

1. Very keen
2. Keen
3. Unsure
4. Neutral
5. Makes no difference

4. Were the financial costs involved in the treatment worth it to you?

1. Definitely
2. Unsure
3. No
4. Definitely not

5. Did the treatment at the clinic pose problems for you at work which necessitated you having to give up work?

1. Yes
2. No

6. Would it be useful if there was a suggestion box at the clinic where patients could make valuable suggestions to the staff regarding the treatment programme?

1. Good idea
3. Unsure
4. Weak idea
5. Will not work

7. Did your religious beliefs pose any problem for you in relationship to the Test Tube Programme?

1. Yes
2. No

8. Which aspect of the treatment protocol, if any, did you have an objection to (Please specify).

9. How did you react to not conceiving on this treatment cycle?

1. Try another cycle
2. Quit
3. Other

10. How would you describe your reactions to an unsuccessful Test Tube Programme?

Satisfied at having tried
Eager to adopt
Angry
Accept not having more children
Empty
Betrayed by my body
Other
Sad
Unfulfilled
Disgusted
Helpless
Hopeless
Guilty

11. Would you have made use of a counselling service if it were made available to you while you were on the programme?

Yes
No

12. What could have been done to help you more during the treatment programme?

_____
_____
_____
_____

13. At which point in the treatment programme did you most feel the need to talk to someone regarding your concerns?

_____
_____
_____

14. Do you think that a subsequent attempt at Test Tube Programme will be as stressful as the first?

_____
Yes_____
No_____
_____

15. In which way have your life plans been affected through not conceiving on the Test Tube Programme?

_____
_____
_____
_____

16. Which past of the programme did you experience as most stressful and what made it so particularly stressful for you?

Waiting to commence_____ Undergoing tests_____
Semen production_____ Ovum pick up_____
Ovum transfer_____ Pregnancy results____
Return of menstruation____

_____
_____
_____
_____

17. Could you list three recommendations to the clinic staff indicating in which way the service delivery on the programme could be improved

_____
_____

Section E
Impact of treatment

1. During the treatment, did you as a couple find a difference in the following areas?

Area	Improved	Same	Got worse
1. Communication			
2. Intimacy			
3. Sensitivity to partner's feelings			
4. Sense of closeness			
5. Ability to solve disagreements			
6. Marital commitment			
7. Marital satisfaction			
8. Frequency of sexual relations			
9. Sexual satisfaction			

2. Did you experience any of the following reactions to the administration of the injections?

1. Fatigue	
2. Weight gain	
3. Headaches	
4. Abdominal discomfort	
5. Irritability	
6. Feeling upset	
7. Decreased sexual interest	
8. Increased sexual interest	
9. Weight loss	

3. Did you experience any of the following symptoms following ovum transfer?

1. Breast tenderness	
2. Closer contact between spouse	
3. Anxiety, thought or dreams	
4. Feelings of happiness and contentment	
5. Less active	
6. Cramps	
7. Pregnancy dreams	
8. Feeling " pregnant "	
9. Nausea	

APPENDIX F

MALE QUESTIONNAIRE

Date of birth_____
Date of marriage_____
Home language_____
Church affiliation_____

Section A

Biographical data

1. Have you been previously married?

   Yes_____
   No_____

2. Number of biological children

3. Number of step children

4. Highest educational qualifications

   1. Std. 8 or lower_____
   2. Std 10 _____
   3. Diploma at Technikon/Technical College____
   4. Diploma at a teaching institution_____
   5. University Education_____
   6. Other_____

5. Have you undergone previous infertility treatment?

   Yes_____
   No_____

6. Is there a history of infertility in your family?

   Yes_____
   No_____

7. How long have you suspected that there is a problem of infertility?

   1. Less than a year_____
   2. One year +_____
   3. Two years +_____
   4. Longer _____

8. What is the given diagnosis of the cause of infertility?

1. Don't remember diagnosis
2. Haven't been told
3. Undiagnosed infertility
4. Blocked or scarred tubes
5. No fallopian tubes
6. Previous tubal ligation
7. Ovulation
8. Male problem
9 Endometriosis

9. What do you think caused the infertility problem?

10. How optimistic were you regarding a pregnancy through the Test Tube Programme?

1. Optimistic
2. Neutral
3. Skeptical
4. Varies
5. Don't know

11. How well did you understand what would be involved in the treatment before you started?

(1 = least understood to 10 - most understood)

1	2	3	4	5	6	7	8	9	10
Least understood									Most understood

12. Have you told others that you are participating on the programme?

Yes
No

13. If yes, whom have you told?
Cross off as many as are applicable.

1. Mother
2. Father
3. Mother in law
4. Father in law
5. Siblings
6. Friends
7. Employer
8. Clergy
9. Other

14. If you have children, did you tell them?

No children
Yes
No

15. How do you usually get through stressful times?

1. By myself
2. Depend on my spouse
3. Friends
4. Other

Section B

Organizational aspects of service delivery

1. Could you follow the content of the brochures given to you at the clinic?

1. Easily
2. Adequately
3. Difficult to understand
4. Unintelligible

2. Was the language in which the programme was written difficult for you to understand?

1. Not a problem
2. Quite a problem
3. Unsure
4. Difficult to understand
5. Unintelligible

3. Did you understand the procedures when explained to you by the doctor?

1. Understood
2. Unsure
3. Not understand
4. Totally unclear

4. Were you asked to attend the initial session together with your wife?

Yes
No

5. If no, would you have liked to be more involved in the procedures, discussions and visits to the clinic? If yes, please specify.

Yes
No

6. Do you feel that enough time was given to you as a husband on this programme?

Yes
No

7. Did you feel comfortable to ask questions in your session with the doctor?

1. Very comfortable
2. Could ask questions
3. Unsure
4. Would not ask
5. Did not feel comfortable

8. Did you understand why blood was taken from both partners?

1. Understood
2. Unsure
3. Didn't understand

7. Did you understand why your sperm was tested?

1. Easily understood
2. Not understood
3. Totally misunderstood

8. How did you as male experience having to produce sperm at the clinic?

1. Comfortable
2. Unsure
3. Uncomfortable

9. Did the sex of the staff member taking you to the semen room matter to you?

Yes
No

Section C

Follow up treatment at the clinic

1. Were you as a husband sure that you understood the reason for the infertility?

Yes
No

2. When you questioned staff about matters related to infertility, did you feel that your questions were adequately answered?

1. All questions
2. Most questions
3. Unsure
4. Insufficient
5. Totally insufficient

3. Would you as a husband have liked to be more involved in the infertility programme?

Yes
No

4. How did you as male feel about talking to a female member at the clinic?

1. Comfortable
2. Unsure
3. Uncomfortable

5. Did you as husband feel that you were partially excluded from the programme?

Yes
No

6. Would you have made use of a counsellor if he/she were made available to you during the treatment programme?

1. Yes
2. Unsure
3. No

6. Which do you think is a better way to inform you of your pregnancy results, telephonically or in person?

1. Telephonically
2. In person

7. Could the staff have been more helpful to you at a time like this?

1. Definitely
2. Unsure
3. No
4. Definitely not

8. Were you involved in some sort of counselling during the treatment process?

1. Yes
2. No

9. Do you think that it is advisable for a counsellor to be made available to each couple while they are on the treatment programme?

1. Yes
2. Unsure
3. No

10. Please make recommendations regarding the clinics follow up procedures after ovum transfer

Section D

Clinic's service delivery

1. How did you experience the atmosphere at the clinic?

1. Warm and friendly
2. Pleasant
3. Unsure
4. Unpleasant
5. Cold and impersonal

2. Did you believe that the information given by you during the treatment was kept confidential?

1. Completely confidential
2. Average
3. Not confidential

3. Were the financial costs involved in the treatment worth it to you as a couple?

1. Definitely
2. Unsure
3. No
4. Makes no difference

4. Did your religious beliefs pose any problems for you in relationship to the treatment programme?

Yes
No

5. Which part of the treatment programme if any did you have an objection to?

6. What could have been done to have helped you more during the treatment programme?

7. How would you describe your reactions to an unsuccessful Test Tube Programme?

Satisfied at having tried
Sad
Eager to adopt
Unfulfilled
Angry
Accept not having more children
Disgusted
Helpless
Empty
Hopeless
Betrayed by my body
Guilty
Bitter
Other

8. What could have been done to help you more on the treatment programme?

9. At which point in the treatment did you most feel the need to talk to someone, if at all?

10. Would it have been useful if there was a suggestion box at the clinic where patients could make valuable suggestions to the staff regarding the treatment programme?

Yes
Unsure
No

11. Have your life plans in any way been affected by your wife not conceiving on the programme?

12. Which part of the programme did you experience as most stressful?

Waiting to commence_____ Undergoing tests_____
Producing semen_____ Ovum pick up_____
Ovum transfer_____ Pregnancy results____
Return of menstruation _____

13. Do you think that a subsequent attempt at Test Tube Programme will be as stressful as the first?

Yes_____
No_____

Section E
Impact of the treatment

1. During the treatment, did you as a couple find a difference in the following areas?

Area	Improved	Same	Got worse
1. Communication			
2. Intimacy			
3. Sensitivity to partners feelings			
4. Sense of closeness			
5. Ability to solve disagreements			
6. Marital commitment			
7. Marital satisfaction			
8. Frequency of sexual relations			
9. Sexual satisfaction			

2. What were your reactions to the unsuccessful ovum transfer?

1. Satisfied at having tried an alternative_____
2. Sad_____
3. Eager to adopt_____
4. Unfulfilled_____
5. Angry_____
6. Accept not having biological children_____
7. Disgusted_____
8. Helpless_____
9. Empty_____
10. Hopeless_____
11. Guilty_____
12. Bitter_____
13. Betrayed by my body_____
14. Other_____

3. As a husband, could you list three recommendation to the clinic staff indicating in which way the service delivery on the programme could be improved.

APPENDIX G

IN DEPTH INTERVIEW SCHEDULE
Guidelines for Exploring Areas

I. **Having Children**

Which partner was the first to initiate discussion around having children

Was a difference of opinion or reservations held around having children

Was there ever a conscious decision made to delay having children

Reason for wanting a children what it would mean not to have one:
- Individually
- Couple

II. **Decision to attempt the Test Tube Baby Programme**

Were you both willing to be involved in this programme or was there a difference of opinion (resistance) held by the partners - if so please explain

Did the issues of infertility and the workup make you feel more vulnerable in the marriage than at any other time

Did you as a couple discuss how many treatment cycles you were willing to try and what would determine how many cycles you are prepared to attempt

What would determine how many cycles you are willing to try

Did you expect to conceive on the programme despite the odds -who was more optimistic

III. **Informed Clientele**

How well informed were you regarding the treatment before commencing on it

What were the kinds of things that you would liked to have been aware of before treatment commenced

Did starting the programme make you feel that you were more in control of your lives

IV. **Who is the Client**

Did the clinic provide you with the option of both husband and wives to participate in the programme - if not what is your thinking around this

Do you view infertility as an individual or a couple problem

If not treated as a couple, did one partner tend to feel excluded? Please elaborate.

How could an excluded partner have been included

V. **Expectations of the Programme**

In which way was the Test Tube Baby programme compare with what you expected on a physical as well as an emotional level

VI. **Support**

Did you find members of the team supportive during the treatement

Could they have been more supportive/sensitive

Who did you confide in while on the programme

In which way would it have been useful to have been allowed access to a counsellor while on the programme

Could you give an indication of the kind of concerns that you would have raised during counselling

VII. **Needs of the Couple**

What are the specific needs facing a husband on a programme such as this

What are the specific needs facing a wife on a programme such as this

How did the infertility issue affect the way you feel about yourself as a man and a woman.

VIII. **Coping**

What helped you personally cope with this treatment?

- Financially
- Socially
- Work time

How did you deal with any failure in the treatment programme along the way

IX. **Meaning of Childlessness**

What is it like to be the fertile partner in this relationship

What is it like to be the infertile partner in this relationship

Who in your opinion carries most of the pain around not having children in this relationship

Do you see infertility as a common problem or that of your spouse

What was the effect of the programme on the marital relationship if any

Could you conceive of the problem of infertility leading to a divorce

What alternatives are you prepared to entertain

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